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By-Kugel, Robert B., Ed.; Wolfensberger, Wolf, Ed.

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Facts about public residential facilities for the mentally retarded in the United States introduce the following subjects personal reactions by an American and by a Scandinavian visitor to typical state institutions for the retarded; the history of U.S. institutions and the theoretical constructs of role and role perception, service concepts which have been successful or feasible innovations including proposals for the improvement of institutions, a presentation of the normalization theoretical construct underlying much of the Scandinavian legal and service structure, continuum of services for the institutionalized retarded, and small, special service residential facilities; and four model service programs located in the urban-metropolitan area of Copenhagen, the rural geographical area of Malmohus County in Sweden, the urban-rural area of Essex County in England (with emphasis on developmental services for severely retarded children and vocational services for retarded adults), and in the State of Connecticut. Proposals of new solutions considered are the importance of viewing residential facilities as human service settings, and a human service system based on a cost-benefit rationale. Also considered are a translation of theoretical notions into concrete proposals and a judgment of these proposals as to their feasibility and priority. (LE)

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changing patterns in residential services for the mentally retarded

a president's committee on mental retardation monograph: 1969

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The President's Committee on Mental Retardation presents this group of papers as a contribution to the careful study and imaginative, people-related thinking and planning which must underlie improvement in services to the nation's millions of mentally retarded persons. The views expressed in these papers are the authors' own; the Committee has taken no position on these works. The Committee's views are presented in two reports made to the President of the United States - - **MR 67: The Nation's Progress and Remaining Great Needs in the Campaign To Combat Mental Retardation** and **MR 68: The Edge of Change.**

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CHANGING PATTERNS IN RESIDENTIAL SERVICES FOR THE MENTALLY RETARDED

Edited by

Robert B. Kugel
University of Nebraska College of Medicine

and

Wolf Wolfensberger
University of Nebraska College of Medicine

President's Committee on Mental Retardation

Washington, D.C. 20201

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CONTRIBUTING AUTHORS

N. E. Bank-Mikkelsen
Danish National Service for the Mentally Retarded

Burton Blatt
Massachusetts Department of Mental Health

Earl C. Butterfield
University of Kansas Medical Center

Robert E. Cooke
The Johns Hopkins University School of Medicine

Lloyd M. Dunn
George Peabody College for Teachers

Gunnar Dybwad
Brandeis University

Karl Grunewald
Swedish National Board of Health and Welfare

M. Michael Klaber
University of Hartford

Robert B. Kugel
University of Nebraska College of Medicine

Bengt Nirje
Swedish Association for Retarded Children

David Norris
Bournemouth (England) College of Technology

Seymour B. Sarason
Yale University

Jack Tizard
University of London Institute of Education

Wolf Wolfensberger
University of Nebraska College of Medicine

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Part I: Challenge

Chapter 1

Why Innovative Action?

Robert B. Kugel
University of Nebraska College of Medicine

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WHY INNOVATIVE ACTION?

The Problem

In 1967, the President's Committee on Mental Retardation took stock of the national effort being made to combat mental retardation. In its report, MR 67 (President's Committee, 1967), one of ten points emphasized was the poor status of residential care. In fact, residential facilities were described as a disgrace to the nation.

Unfortunately, there is little good news when writing about residential facilities in the United States, although considerable and even outstanding progress is being made in some areas of mental retardation. Among these are the growth of day centers for severely handicapped individuals and of employment opportunities for retarded and handicapped individuals in general. Throughout the country, programs in public education have helped to dispel some of the darkness of the past. Research--biological, sociological, and behavioral--is a hallmark of the American scene. Volunteer efforts for both the retarded and the physically handicapped have been outstanding. Innovations in behavior shaping are pointing the way for better management. Diagnostic services for the retarded also have been among the outstanding successes.

Why, then, have residential facilities in this country lagged so far behind these other areas in which advancement has been considerable? What are some of the problems which seem to confront our residential facilities?

Typically, public residential facilities have been plagued by a triple problem: overcrowding, understaffing, and underfinancing. To complicate matters further, the public, long accustomed to knowing little about mental retardation, often held inaccurate information, and there was a mystique about the retarded and other handicapping conditions involving feelings of hopelessness, repulsion, and fear. Gradually a change in attitude has been occurring as various significant efforts have been made to enlighten lay and professional people alike. But despite these efforts, the residential facilities of this country have languished. I would like to analyze briefly some reasons why public and, to some extent, private residential facilities throughout the country are so far behind.

In the mid-19th century, there was a wave of optimism about the care of the mentally retarded. The belief developed at that time that, through educational efforts, the retarded could be helped, and that most of them could be made self-sufficient citizens. When this concept, so noble in its beginning, appeared to have failed, decision-makers became committed to locating institutions away from the population centers of the state. This unfortunate decision seems to have been motivated in part from the conviction that mentally retarded persons were best cared for in a more bucolic setting; in part out of fear that the retarded, being a scourge to society, should be removed as far from society as possible; and in part to satisfy demands to locate employment opportunities in underdeveloped areas in order to provide jobs and income to the surrounding communities.

Still later, the scourge notion grew, especially with the publication of poorly designed studies like that of the Kallikak family by Goddard (1912). The mentally retarded were soon to overpopulate our land, according to Goddard, and segregating them from society was the most important service to be rendered. As a consequence, further building programs for institutions were really a continuation of the out-of-sight, out-of-mind concept, and institutions for the retarded began to be considered as colonies where the undesirable members of society would be segregated and separated. Although this concept also proved to be fallacious, the country soon entered World War I, which was followed not long afterwards by the Great Depression, and these events permitted the mold to set, so that very little in the way of changes occurred for many years.

For whatever reason or combination of reasons, most of the nation's public residential facilities, and also many private ones, are located in out-of-the-way communities. Being so located has meant ever-increasing difficulty in obtaining qualified professional staff, who frequently prefer to live in larger communities. Similarly, the core of any institution, i.e., the ward or cottage personnel, have been increasingly difficult to recruit as the population has shifted from rural to metropolitan areas.

When citizens become concerned about an issue, such as where to locate a new highway or whether to build a new school, it has always been useful to be able to show these citizens, their legislators, and others in decision-making positions what the problem is all about by having ready access to a good existing example. This has been a problem for those trying to change the plight of the institutions, because it is doubtful whether there is a single exemplary model of care for the severely and profoundly retarded anywhere in this country.

To visit institutions, exemplary or otherwise, citizens in the past had to make a great effort, and then they often went only once. In part, this is so because of the distance involved for many, and in part because they were repulsed by what they saw. Many legislators have appropriated large sums of money to support their public facilities, but have never visited a single institution for the retarded, either to see the need firsthand or to ascertain how the money was spent. There are physicians who refer families to these residential facilities but who have never seen the facility and do not know the professional personnel caring for the clients whom they refer. This is an odd paradox since one cannot imagine a physician referring a patient to a hospital for an operation if he knew nothing about the place and people involved.

The underfinancing of most public institutions is a tremendous problem. The 1966-67 per diem costs over the country (excepting Alaska) range from about $3 to $14. (U.S. Department of Health, Education, and Welfare.) In contrast, five of the largest zoos even a few years back spent an average of over $7 for their large animals (see Blatt in this volume). While capital construction outlay and total operating budgets of institutions involve vast sums of money, budget increases, especially increases in per capita expenditures, have often been so token that very little help was given to the beleaguered institutional superintendent and his staff.

The underfinancing pertains to all aspects of residential care; it contributes, of course, to the understaffing. Salaries have often been at shockingly low levels. In many states, professional salaries have been at levels so low as to attract no one of competence, and the nonprofessional salaries for attendant personnel in many places have been below the national poverty level! Physical therapists are frequently lacking altogether. Speech therapists may consist only of untrained individuals. Occupational therapists may be totally unknown. While the children and adults may be kept clean, they often have no programs for daily living other than the meaningless blare of a television set or the completely empty, fenced-in court. Can anyone doubt that such practices have interfered severely with effective programming?

Many institutions have been so hard put to attract capable medical personnel that they have relied heavily on foreign-trained physicians, some of whom were unable to secure state licenses and hence were able to work only in a facility which could waive state requirements, such as is possible by a state facility. Unable to go elsewhere and being the only ones willing to accept the poor salaries, these men and women find themselves in virtual bondage, and the salary situation remains poor. Other institutions, even if large, have no full-time physician at all.

On the basis of some rough calculations it is estimated that about 30 percent of all budgeted positions in public residential facilities are now vacant (Noone, 1967). This can be explained partially by the fact that the attendant positions of many of our institutions are at the level designated by our government as poverty wages. Three thousand dollars a year will not provide personnel of high caliber! Since the cottage life and ward personnel constitute the backbone of any residential program, it should not be surprising to find that many habilitative programs are frequently seriously inadequate or lacking altogether.

The use of residents to perform work necessary to keep the institution running constitutes another problem which arises from underfinancing and which is sometimes referred to as "institutional peonage." Although it is highly desirable that residents be productively employed, continued and inappropriate retention of residents in work situations has often been the only way the daily work could get done. Some important services in the ward, infirmary, maintenance, laundry, and kitchen areas would collapse if it were not for continued reliance on resident help. In addition, absence of adequate community resources (e.g., workshops, group living facilities, community supervision) has meant that even if residents were to be released, there is often no place for them to live and no job for them to have. To habilitate the retarded person who has lived the better part of his life in an institution is most difficult, since he is ill-prepared to cope with the social requirements of a normal community.

The American Association on Mental Deficiency is currently evaluating our residential facilities. This is a voluntary process, and residential facilities are not obliged to submit. However, most of them do, and many are reporting that they are grossly overcrowded, being anywhere from 25 to 50 percent above their rated bed capacity (Blatt and Kaplan, 1967). Consequently, there are often large bleak wards where physically handicapped individuals are confined to bed, provided with minimal care, but given little in the way of stimulation to make their lives the least bit meaningful. Many will end their days in these drab surroundings. There is still an additional factor: increasingly, severely handicapped residents with multiple problems are being admitted because many such individuals, who would have died a generation ago, are now saved as a result of medical advances.

Recently, Blatt and Kaplan (1967) published a book entitled Christmas in Purgatory. In this book they indicated pictorially the deplorable state of some residential facilities. Although the authors were criticized by some, I believe that Blatt and Kaplan have performed a great and important service by pointing up this shocking problem. We all know of places where residents sit naked, surrounded by their excreta. I have seen a man without legs condemned to walk on his stumps because he once ran away from the institution, got lost, froze his legs and had to have them amputated. Everyone was reluctant to provide him with rehabilitative services for fear that there might be a repetition of this behavior, and, furthermore, his condition was perceived as a deserved punishment!

Overcrowding, understaffing, and underfinancing are three of the important issues related to public facilities, but there are others. One of these is obsolete architecture and design. Maintenance may have been so poor that lavatory and toilet facilities may be nonfunctioning, food preparation cannot be carried out in the desired sanitary fashion, and climate control may be so unequal to the task as to leave buildings either too hot or too cold.

Many Americans have the impression that poor residential facilities are something inevitable which must be endured, along with other evils of our times. Not so! One can visit several European countries, especially in Scandinavia, to find imaginative and unusual programs of care. Along with others, I have been impressed on my visits there to find many residential facilities which were located close to population centers. In Copenhagen I visited a residential facility (Children's Hospital at Vangede) which is in a suburban setting served by the city's rapid transit system. Many of these facilities have no more than 150 to 200 residents, and some are no larger than a large household. Staff-to-resident ratios are frequently 1:1, and the care provided is exemplary. In addition, the physical surroundings are pleasant, abounding in bright colors. Fixtures and furnishings are attractively designed and not the clumsy institutional or prison industry furniture often found in this country. Everything is meant to be attractive and to have appeal to those who must reside in such a facility.

The problems of our overcrowded institutions can only be solved by giving simultaneous attention to community resources. It has been pointed out on many occasions that the galaxie of services needed should include diagnostic centers, special education, day care, vocational training, sheltered workshops, residential schools, group living homes, etc. I would maintain that residential facilities will not be what we want them to be unless simultaneous efforts are made to rectify the situation in both the institution and the community.

As one major effort towards accomplishing the desired objectives, massive re-education is required. There is nothing to be gained by hiding the fact that our residential facilities are in a deplorable state, their buildings crumbling, the staff overworked, underpaid and often undertrained, and the programs providing only minimal care and habilitation. Each state must develop a greater public education effort to bring to the attention of the citizens this blot on our escutcheon. It should be our wish and intent to try to rehabilitate residents to the community, rather than to segregate them. This reorientation in thinking will require considerable effort as public officials, administrators of institutions, professional workers, and the lay public all come to understand that the handicapped and the retarded do not need to be moved aside, but rather should be a part of the ongoing community process.

Group homes, nursing homes, and respite centers which provide short-term residence in an effort to help families and to meet temporary needs should all be part of the services available in the community. Even severely retarded individuals with extensive physical handicaps can be handled in the community. Great Britain some years ago pioneered with the idea that the physically handicapped, as well as the person with other handicapping conditions, can and should be maintained in the community; but to do this, the concept was developed that even the most severe form of handicapping condition requiring prolonged nursing care could be cared for in the community as part of a regular pediatric unit.

Such services need not be separated, segregated and removed from society (Pediatric Society of the South East Metropolitan Region, 1962).

One might ask the question, Should not all such persons be maintained in the community? Why should they be removed? Should not society's aim be to try to help when mental retardation or physical handicap has occurred? One does not say to the parent of a child with leukemia that the child should be "put away," although everyone knows that the child will ultimately die, and understands the human tragedy which has occurred. Rather, all forces are mobilized to help and to sustain the child in the community even though he may need periodic hospitalizations. Surely the same approach should be used for the mentally retarded and the physically disabled.

In the easing of understaffing, two programs are worthy of note. The Foster Grandparent Program (under which the government pays retired citizens to engage in one-to-one work with retarded persons for a few hours a week) has been successful in helping to cope with the manpower problem. It meets the needs not only of handicapped persons but also of the elderly who are looking for a constructive role in our society where they can be of help and assistance and not be thought of as misfits, relegated to a shelf. The SWEAT (Student Work Experience and Training) program has been another successful device in attracting people, in this case youths, to mental retardation. Under this federally supported program, high school and college students are paid a stipend for working during a summer in a facility or service for the retarded. In many such programs conducted across the country the students have received didactic instruction along with the work experience. SWEAT has been one of the most imaginative as well as economical and apparently successful projects attracting young people to careers in this field. But much more is needed, and much greater effort will be required if the manpower problem is to be solved.

Throughout the Scandinavian countries, I have been greatly impressed by the numbers of young, eager, well-informed men and women one finds working with the retarded. At a school for cerebral palsied children in Gothenburg, Sweden, I had the opportunity of visiting one of the most delightful places to be seen anywhere. This happened to be a residential facility where things are so well developed that one could find a child who was ill (from some other cause) being read to rather than being left alone, as is so frequently the case in our country.
A training program in Denmark for primary workers in mental retardation (equivalent to our attendants) is of considerable interest. The program is half theoretical and half practical. The students, many of them akin to school dropouts in this country, are recruited for such training, subsidized during it, and thereafter provided with good situations in which to work. A similar program has been in existence in at least one area in England.

While the turnover is fairly great among the young people in Scandinavia who are trained in these programs, there is another sidelight to all of this. Most of these young people will go on to be parents themselves, and having learned something about the handicapped as well as something about child development, they will be more understanding of the handicapped and also will be in a better position to manage their own families. At any rate, it can be noted that these ingenious training programs have come close to solving the personnel problem. This idea should be studied carefully by all of our states to see what can be adapted to the American scene.

In thinking about solutions for residential care, one certainly must give thought to architecture and size. Dr. Gunnar Dybwad has written much about the architectural barriers in residential facilities. He and others would point out that if existing buildings are to be modified in order to relieve overcrowding, a loss in bed space is inevitable. On the basis of 10 to 15 years of experience, the Scandinavian countries, again leaders in the remodeling of existing buildings, have pointed out that it is absolutely necessary to plan on reducing the number of beds by half in order to bring many old buildings up to modern standards.

The desirability of having large facilities of 1,000 or more is still controversial. Many of our facilities are of this size, or larger, and some more are now being constructed. The evidence is not convincing as to why large residential facilities need be built. The argument often runs that large facilities cost less to operate. I would suggest that this point has not been proved. Currently, the President's Committee on Mental Retardation is in the process of having a study conducted concerning what is known about costs of running large versus small facilities. There is preliminary evidence to suggest that small facilities of 150 to 250 can be constructed and operated at no more than the cost now being utilized in the larger residential facility, and perhaps even at less cost. It is even possible that the hostel concept of placing small groups of retardates into existing rented, leased, and purchased homes and facilities (rather than newly constructed ones) will prove the most economical alternative for many retardates needing residential care. Existing facilities are often cheaper than new construction, and rentals and leases preserve the flexibility of locating and using facilities as needed--a flexibility that is drastically reduced in new purpose-built construction. Cost analysis can be deceptive, however, if one is not comparing like commodities. The study will, I believe, shed some important light on the entire matter of cost accounting in the operation of these various facilities.

An additional point to be made about the size of an institution certainly relates to one's sense of human values. In today's world, where many of us become numbers on an IBM card, we feel great reluctance to bid farewell to the concept of a more individualistic approach to human services. Increasingly, people express preference for return to small units and systems, whether in a university, a city, or a residential facility. These human values must not be permitted to be overshadowed by too much architectural efficiency and the engineering consideration of locating buildings at the point closest to the steam plant. Surely we have seen the problems of regimentation so as to be ever on guard in all sectors lest we increase or even perpetuate this problem.

I have not written much about which one can be happy. Individuals and groups concerned with the handicapped and retarded should make every effort to join hands with each other to see what can be done to improve this deplorable situation. I would suggest that the reorientation of the community will be the crucial factor. Facilities close to where people live should be the watchword. At the same time, we must attend to the condition of our existing facilities, to improving the pay scale, to reducing the number of residents, and to restructuring the mission of residential facilities in ways which will return residents to the community.

The Rationale of the Book

The President's Committee on Mental Retardation has been deeply concerned about the issues sketched above. The Subcommittee on the State of the Nation was instructed to give serious study to this problem in 1967/68. As chairman of the Subcommittee, I have invited several American and European leaders known for imaginative conceptualization, planning, construction, or administration of residential and other services to take a thoughtful look at the plight of our nation's residential programs and facilities for the retarded, and to put their thoughts on paper. No attempt was made to develop an exhaustive handbook on residential care, but to examine the present system and to delineate some alternatives and courses for action.

While the focus of this effort was to be on residential services in the United States, it became obvious that one cannot look at the residential problem without addressing oneself broadly to all aspects of services to the retarded, and even to human services more generally; and that in examining our problems, we can both learn from and perhaps contribute to the experiences of our colleagues in other countries.

The compendium of papers was intended to serve as a resource to the Subcommittee, and ultimately the total Committee, in formulating recommendations to the President and the nation. However, it was felt that the thinking of the authors should also be brought before a wider audience, and that this compendium that has contributed so much to the deliberations of the President's Committee should be published. Specifically, an attempt was made to structure the contributions to this volume in such a way as to make them useful not only to specialists in the field but also to nonspecialists who can or must make decisions relevant to the future of the field. Among such individuals might be legislators, officials at various levels of local, state, and federal government, and parent leaders. Last but not least, it was hoped that part or all of the book could be useful to students of mental retardation.

The rationale for the composition of the book deserves some discussion. The concept of "models" underlies the entire book and ties its various elements together. First, we attempted to provide an understanding of the current situation, i.e., the current models, and the first four parts (five chapters) of the book are devoted to this. The next three parts (eleven chapters) introduce suggestions and examples for constructive change (new models). The last part attempts to digest and integrate all of the earlier chapters and to translate them into specific recommendations for action. Appendices were added to a number of chapters. These appendices contain material that would disrupt the continuity and balance of a chapter, but which provide documentation or elaboration that might be of high interest to some users of the book. A more detailed discussion of this progression of the book follows below.

In Part 2, immediately following this chapter, Butterfield presents an array of basic facts about public institutions for the retarded in the United States. The intent of this chapter is to inform the nonspecialist and foreign reader of some quantitative aspects of the problem and to serve as a reference source to others. It should be noted that other chapters frequently make reference to the type of data presented by Butterfield.

Part 3 contains accounts of personal reactions to visits of rather typical state institutions for the retarded. Blatt's chapter is related to a book (Blatt and Kaplan, 1967), repeatedly referred to by other authors in the volume, and to an article based on this book and published in Look. Blatt depicts realities which many of us would prefer to deny, but which can only be called inexcusable for a wealthy nation such as ours. Indeed, such conditions are a disgrace to the nation, as should be clear from the next chapter by Nirje.

Nirje brings a perspective to bear which can be very valuable to us. Highly knowledgeable of mental retardation services across the world, he visited the United States with few preconceived ideas of what he might see, and--what is particularly painful to us--he had no axe to grind or vested interests to represent; thus, only someone with a strong vested interest himself could dismiss his judgment of our institutions lightly.

To understand the present and minimize errors in the future, one must know and understand the past. In Part 4, Wolfensberger attempts to interpret the history of United States institutions for the retarded in the light of certain theoretical constructs that have gained prominence in recent sociological thinking. A construct of particular strength in Wolfensberger's analysis is role and role perception. According to this analysis, our institutions generally function as if their retarded residents were perceived either as a social menace or as subhuman organisms, and institutional reform will depend more on changes in ideology than on vast monetary expenditures.

Wolfensberger's documentation of various trends may appear to be excessive, but was retained because of historical circumstances: in challenging some widely accepted views, and in attempting the first major reinterpretation of the development of retardation institutions, it was felt necessary to provide solid substantiation. Otherwise, his interpretations might be dismissed as ill-founded, highly personalized hypotheses.

The first five chapters, Parts 1-4, essentially represent attempts to define and understand a problem, and to set the stage for thoughts about constructive action. In Part 5, various authors present service concepts which have either already been tried and found highly useful, or which, if untried, are relatively logical and feasible innovations.

In the first chapter of Part 5, Blatt presents some proposals on how to improve institutions if we must have them. These proposals, of course, stem from the observations he discussed in Chapter 3.

In the next chapter, Nirje, too, puts the observations he recorded earlier (in Chapter 4) into perspective. He presents the theoretical construct of "normalization" which underlies much of the Scandinavian legal and service structure in mental retardation. This construct has never been fully presented in the American mental retardation literature, but it is of such power and universality as to provide a potential basis for legal and service structures anywhere. Indeed, the editors of this book view the normalization principle as perhaps the single most important concept that has emerged in this compendium.

Blatt presented specific measures for institutional reform, and Nirje a broad theoretical framework for retardation services generally. At this point, Tizard and Dunn present chapters on practical, even administrative, aspects of service development and structure. Tizard treats the problem of determination of service needs, balance of service provisions, and the place of residential services within the service continuum. In a sense, he brings close to us the service concepts which were advocated in the 1962 Report by the President's Panel on Mental Retardation, but which so far have been implemented in only very few instances in this country, and even then only partially so.

It is quite likely that even without any further theoretical or empirical elaboration there would be a trend toward dispersement of residential centers. However, Dunn warns that while dispersement is highly desirable, it may not be enough. Both for programming and staffing reasons, he urges that residential facilities be not only small and dispersed, but that specific professional disciplines should operate different facilities according to their own service models, specializing upon the management of relatively homogeneous groups of residents.

A theme brought out again and again in this book is the need to include, view, and discuss residential facilities as only one component of a continuum of services. Nothing is as convincing of the viability of such a broad service system as visiting and seeing one in operation. Since this book cannot provide an actual visit, we decided to do the next best thing and present detailed descriptions of four model service systems. To serve as a model, the following requirements had to be met:

1. A model had to consist of a clearly circumscribed, currently functioning, entity, so that it could be unequivocally identified, described, and seen in operation by those desirous of visiting an operating exemplary system.

2. In order to demonstrate the feasibility of continuity of services, the model had to contain a range of services of which residential facilities were one part.

3. In order to be instructive in regard to administrative and planning aspects, the model had to be in a dynamic state of evolution according to a well-conceptionalized and formally defined (written) planning scheme.

4. Since services to the retarded are increasingly perceived as a right, and since services defined as legally rightful tend to be operated or at least regulated by governmental units, a model had to be operated or regulated under public auspices in order to be maximally instructive.

5. Long-term planning is not very feasible or meaningful unless the plan is for a well-defined geopolitical area. Because of this consideration, as well as the requirements of items 1 and 4 above, a model was required to be associated with a well-defined geopolitical unit.

6. Someone intimately familiar with a potential model service system had to be willing and capable of rendering a global, balanced, well-written description of it.

It was felt that these requirements would not only yield the most instructive examples, but that these characteristics would be those held by most service systems considered most exemplary by leaders in the field. It was with such leaders around the world that we consulted in order to identify service systems that would meet our criteria and be considered exemplary. To our surprise, very few systems were considered exemplary by these experts, and not all of these met the requirements. In the United States, despite extensive consultation, we would identify only one service system that came even close to satisfying the criteria. From other countries, three models emerged as suitable. Thus, a total of four model service programs were finally identified, described on paper, and presented in Part 6.

The head of the Danish National Mental Retardation Service, Bank-Mikkelsen, describes the first model. This model involves an urban-metropolitan area, i.e., Copenhagen, which is one of 11 service regions of Denmark. Of special interest here is the extensive application of normalization principles, as described by Nirje, to a service system. Similarly, this principle is expressed in Grunewald's description of Malmöhus County in Sweden, a geopolitical area which, in contrast to Copenhagen, is mostly rural in nature. These two chapters, together with material presented by Nirje in Chapter 7, provide a great deal of information on the legislative underpinnings of services of two countries considered exemplary in many aspects of mental retardation provisions.

In Chapter 12, Norris describes the services of Essex County in Britain. This county is widely regarded as a model in Britain. Also, while Scandinavia appears to lead in the elaboration of residential provisions, some counties in Britain are more advanced in developmental services for severely retarded young children and in vocational services for retarded adults. This type of emphasis clearly emerges in the Essex system, especially in relation to the large number of sheltered workshop places provided or planned by that system.

Finally, the service system in the State of Connecticut is described. In including this description by Klaber, it is not intended to present the Connecticut model as an ideal or even desirable model for all states and areas. However, it is intended to show how an attitude of dissatisfaction, combined with relatively consistent concepts, has led to popular acceptance of a new service system that is vastly preferable to the old one, and that is superior to most systems now existing in the United States.

Part 7 contains three chapters which, in some ways, are similar to those contained in Part 5, since they present service-related issues and propose new solutions. However, these three chapters are presented separately because they either go far beyond the thinking of Part 5, or because the models in Part 6 do not exemplify the content of these three chapters.

In the first chapter of Part 7, Sarason makes a number of critical points. One of these is the importance of viewing residential facilities as human service settings generally, all subject to similar social processes, dynamics, and trends. Secondly, those in the human service area will fail to understand and control events unless they view the operation of their settings from a larger social system viewpoint, rather than the narrow, individual-oriented clinical perspective of traditional service agencies. Finally, Sarason, points to the importance of consciously conceptionalizing an ideology and a concomitant set of general practices from the very inception of a setting, and letting these rule the specifics of operation rather than the reverse.

The next two chapters contain service conceptionalizations which might be interpreted as being "typically American." Cooke proposes an extension of Medicare principles and legislation to permit public moneys to be used to pay for private residential services selected by the parents. He feels that such an approach would quickly result in the development of numerous small, dispersed, residential homes; that presently unutilized manpower would come forth to serve in these facilities; and that these facilities, being of high quality since they would have to meet stringent requirements, would "drive out" big and poor institutions.

In the third chapter of Part 7, Wolfensberger presents what appears to be the most radical innovation suggested in this book: a human service system based on a cost-benefit rationale. He suggests that residential services in retardation should be considered not only an integral part of a wider retardation service system but part of a broad system of human services generally. The publicly supported part of this system, he feels, should be reorganized so as to reduce the autonomy of service agencies, and decision-making regarding specific service allocations should be based on considerations of how service benefits can be maximized for the largest number of citizens, given the limited resources available at any one point in time. Perhaps this proposal is utopian--perhaps it is prophetic. Indeed, the cost-benefit concept is gaining in ascendancy in industry, Congress, and elsewhere, and the question of national priorities that is now widely discussed for the first time is closely bound up with cost-benefit notions.

The final part and chapter of this monograph is written by Dybwad, one of the most prominent thinkers about mental retardation services in this country, and perhaps the world. In this chapter, he attempts to interpret and place into perspective the contributions of the other authors. Most importantly, from the vast amount of problems, issues, examples, and solutions discussed, he attempts to isolate implications on various levels of action and implementation. From the material presented in the preceding parts of the book, he attempts to translate theoretical notions into concrete proposals, and judge concrete measures as to their feasibility and priority in the America of today.

The editors are most grateful to all of the contributors of this book. For each contributor, it meant working against a deadline, but all were willing to take time from exceedingly busy schedules to add their thoughts to this volume.

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Part II: Situation

Chapter 2

Basic Facts About Public Residential Facilities for the Mentally Retarded

Earl C. Butterfield
University of Kansas Medical Center

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BASIC FACTS ABOUT PUBLIC RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

National Statistics

More than 200,000 people, nearly half of whom are children, now live in over 150 public institutions for the mentally retarded in the United States. Another 20,000 retarded reside in approximately 500 known private facilities. Tens of thousands more wait out their times in institutions for the mentally ill; nearly 10 percent of all residents in public mental hospitals are retarded.

The number of institutionalized mentally retarded increases by over 3,000 every year. Public institutions for the mentally retarded alone admitted an average of over 15,000 every year between 1960 and 1967. Over half of these were under ten years of age. An average of only 8,000 was released from public institutions each year from 1960 to 1967, and approximately 3,000 died while institutionalized during each of those years. Accurate statistics concerning trends in the numbers of retarded residents in private institutions and in public facilities for the mentally ill are not available. Estimating from the number of retarded people in these facilities, they probably accommodate an additional 300 to 400 retarded each year over and above the more than 3,000 who are annually added to the rolls of public facilities for the retarded.

The fact that thousands are admitted to public institutions for the retarded each year does not mean that gaining admission is easy. It is exceedingly difficult, because institutions are generally filled. The average institution houses 98 percent of the number of residents it states it can accommodate, and most facilities are overcrowded and understaffed when they are operating at their stated capacity. Many institutions house more than their stated capacity. Some contain 50 percent more people than they were constructed for. In 1962, the President's Panel on Mental Retardation estimated that 50,000 bed spaces would have to be constructed to alleviate institutional overcrowding and to replace inadequate facilities. There is little reason to believe that fewer new beds are needed now.

Since most public institutions operate at or above their capacity, the delay between applying for and gaining admission is usually great. Often it is more than 3 years. Also, who is admitted is often determined by who has been released rather than by the needs of the applicants. A bed vacated by a mildly retarded female is usually given to a mildly retarded female even though aged males or severely damaged infants may be in graver need and have waited longer for admission. The crowded condition of institutions also produces long waiting lists. Most institutions would have to expand by more than 25 percent in order to eliminate their current waiting lists. Even such large-scale additions of beds would probably not shorten for long the lines of those who await admission. Experience has shown that people who have not applied before the construction of new facilities, for lack of hope of ever being admitted, come forth to seek admission and to refill the waiting lists when new facilities are opened. We are forced to conclude that many who need residential services have not applied for them.

Even though fewer than 5 percent of the mentally retarded in the United States reside in institutions, more money is spent to maintain them than is spent for any of the public programs which serve the remaining 95 percent. The annual cost of maintaining this country's public institutions for the retarded is now greater than 500 million dollars. In 1966, the national average operating cost per day per patient under treatment was $6.72. General hospital care cost more than $40.00 per patient per day during 1966.

More than three-quarters of the $500 million spent each year to maintain public institutions for the retarded goes for the salaries of institution personnel. More than 90,000 people are employed full time in public institutions for the retarded. Of these 90,000, more than half are attendants whose job is to give direct physical and emotional care to the retarded. In 1965, there was one attendant for each four residents in public institutions for the retarded. However, since attendants must provide around-the-clock coverage, the one-to-four ratio overestimates the amount of resident-attendant contact. Nevertheless, attendants have more resident contact than other types of employees combined, as may be seen by the fact that there was only one physician for each 270 residents, and only one psychologist for each 430 residents. Attendants are the main executors of institutional programs. They are faced with an incredibly wide array of responsibilities, ranging from being a substitute parent, janitor, and record-keeper to being part nurse, part physical therapist, part psychologist, and part educator.

Despite the fact that attendants are the most important people in the lives of the institutionalized retarded, the vast majority of them come to their job with no relevant past experience. They have been farmers, factory workers, career soldiers, housewives, etc. They generally have no particular educational qualifications. The majority come to their positions with less than a twelfth grade education. In most institutions, attendants come and go more quickly from their positions than any other group of institutional employees. A survey of 26 institutions in the 16 southeastern United States showed that, on the average, 20 percent of attendants are replaced in a year. In two of the 26 institutions, fully 50 percent of the attendants were replaced in one year.

A large part of the reason for the undistinguished qualifications of attendants and for their high turnover rate is undoubtedly the low status they are accorded and the niggardly pay they receive. Among the majority of the 26 institutions just mentioned, the maximum possible salary for attendants was more than $1,000 below the median income of the families in the county in which the institutions were located. In only 9 instances was the maximum equal to or greater than the median of the families in the surrounding county. Few attendants earn the maximum salary. Most attendants earn less than $350 per month. Many earn far less than this.

About 11 percent of the 90,000 persons employed in public institutions for the mentally retarded are classified as professionals. Most of these are teachers and nurses. Fewer than 2 percent of all institution personnel are classified as psychiatrists, psychologists, and social workers. Data on the precise qualifications and credentials of those persons classified as professionals in public institutions for the retarded are not published. Those listed as psychologists, social workers, and teachers often have not completed standard educational programs, although most probably have an undergraduate degree of some sort; particularly those listed as physicians, dentists and teachers cannot be assumed to meet standards required for working in the community.

The information which is available concerning the credentials of professionals employed in public institutions for the mentally retarded suggests that they are not, as a group, among the most highly qualified in their fields. For example, hardly any physicians are boarded in their specialties. Many cannot even be licensed for private practice in the states in which they treat the retarded. Most institutional psychologists do not have a Ph.D. degree, and cannot, therefore, even apply for certification by the American Board of Examiner's in Professional Psychology. The situation is similar for social workers, most of whom do not hold a Master's in Social Work degree. As with attendants, the lack of status and the relatively low pay associated with professional positions in public institutions probably account in large part for the apparent lack of distinction of most institutional professionals.

State and Regional Differences

The population of public residential facilities for the mentally retarded is 55 percent male. Eighty-two percent are reported to have IQs below 50 (see Table 1). The high percentage of profoundly, severely, and moderately retarded suggests that the majority of the institutionalized retarded require intensive care and supervision. This is particularly true since approximately 50 percent of all residents are below the chronological age of adulthood (see Table 2). National statistics such as these give needed perspective on residential facilities for the mentally retarded. However, they also obscure important differences between institutions. Maintaining public institutions for the retarded has been the responsibility of the separate states, and as states' philosophies, policies, and resources have varied, so have their institutions.

Table 1*

Distribution of Residents According to Level of Retardation

	Number of Residents	Percent
Levels of Retardation		
Profound	51,973	27
Severe	63,523	33
Moderate	42,348	22
Mild	25,024	13
Borderline	9,625	5
Total	192,493	100

* Adapted from Milligan and Nisonger, 1965.

Table 2*

Distribution of Residents According to Chronological Age

Chronological Age	Number of Residents	Percent
0 - 4	5,775	3
5 - 9	21,174	11
10 - 14	30,799	16
15 - 19	32,724	17
20 - 24	28,874	15
25 - 29	23,099	12
30+	50,048	26
Total	192,493	100

*Adapted from Milligan and Nisonger, 1965.

States differ dramatically in how many and what types of their retarded they serve. The public institutions for the retarded of Kentucky, Arkansas, and West Virginia house approximately 3 people for every 10,000 in their general population, while Wyoming, South Dakota, and North Dakota house about 20 persons in their public institutions for the retarded for every 10,000 in their general populations. The remaining states distribute themselves between these extremes in the manner shown in Table 3. Tables 4 and 5 reflect differences between the states in the types of retarded served. Table 4 shows the percents of each state's institution population which fell into the various levels of retardation. Table 5 shows the number of residents admitted to the various states' institutions during 1965 and the percents of those admitted who fell into the various levels of retardation.

Undoubtedly many factors underlie the differences between states in the proportion and types of their retarded which they serve in institutions. There is considerable diversity among the states in the most basic issue of the definition of mental retardation. Although most states have only one admission procedure, many have several procedures by which a person can be placed in an institution for the retarded. States differ in the number and quality of noninstitutional programs for the retarded, so that a person who would be served in the community in one state must be institutionalized in another. Charges to patients for institutional care differ markedly from state to state. Discharge policies and rates vary from state to state, so that in some, beds become vacant more frequently than in others. Some states have expanded their institutional facilities more than others (see Table 7).

States also differ in how much they spend to maintain a person once he has been institutionalized and in how they allocate those expenditures. Per patient daily costs range from about $3.00 in Mississippi, South Dakota, and Nebraska to about $12.00 in Kansas, New Mexico, and California. The per resident daily costs of the various states during 1966 are shown in Table 6. Table 7 shows some of the differences between states in how they allocate their maintenance expenditures. It also shows how much the states differ in their capital expenditures for improvements and additions to their institutional facilities. In 1965, more than 20 percent of the expenditures of the states of Indiana, New York, Tennessee, and Wisconsin for the institutionalized retarded went for improvements on additions, while Alabama, Massachusetts, Minnesota, North Dakota, and West Virginia spent no money for improvements or additions.

States also differ in the numbers of different types of employees they use to serve their institutionalized retarded. For example, in Georgia, Mississippi, and Nebraska there is only one physician for each 600 residents, while in California, Maine, and Wyoming there is a physician for each 150 patients. Similar differences for other types of employees are shown in Table 8.

Table 3*

1966 Residents in Institutions for the Mentally Retarded per 10,000 Population, by State, and Daily Maintenance Expenditures

State	Institution Residents per 10,000	Rank	Daily Maintenance Cost per Resident	Rank
Wyoming	22.00	1	$6.50	33
South Dakota	19.33	2	3.17	49
North Dakota	18.90	3	4.39	45
New Hampshire	16.76	4	5.60	39
Nebraska	16.45	5	3.58	48
Vermont	16.37	6	5.76	38
District of Columbia	16.28	7	6.58	32
Massachusetts	16.09	8	6.69	31
Minnesota	15.34	9	5.95	35
Michigan	15.03	10	8.07	14
New York	15.02	11	6.94	29
Oregon	14.79	12	7.02	28
Montana	14.73	13	5.00	42
Washington	14.01	14	7.36	21
Connecticut	13.70	15	8.82	7
Hawaii	12.17	16	8.31	12
South Carolina	11.82	17	3.90	47
Delaware	11.45	18	7.17	23
Utah	10.94	19	5.86	37
Rhode Island	10.56	20	10.64	5
Idaho	10.54	21	7.13	24
Maine	10.20	22	8.66	9
Pennsylvania	10.05	23	7.09	26
Colorado	10.01	24	8.55	10
Ohio	9.71	25	5.08	41
Texas	9.61	26	4.88	43
New Jersey	9.49	27	7.13	25
Illinois	9.20	28	7.54	18
Wisconsin	9.06	29	10.63	6
North Carolina	8.97	30	6.92	30
Kansas	8.81	31	12.18	2
Maryland	8.43	32	7.72	17
Oklahoma	8.43	33	8.05	15
Indiana	8.04	34	7.42	20
Virginia	8.02	35	4.71	44
Florida	7.61	36	7.32	22
California	7.11	37	11.41	4
Iowa	6.78	38	7.97	16
Alabama	6.45	39	4.04	46
Louisiana	6.36	40	8.23	13
New Mexico	6.07	41	12.11	3
Missouri	5.70	42	6.36	34
Mississippi	5.62	43	2.30	50
Arizona	5.56	44	5.38	40
Tennessee	5.39	45	5.92	36
Georgia	4.37	46	7.47	19
Kentucky	3.46	47	8.44	11
Arkansas	3.38	48	7.07	27
West Virginia	2.61	49	8.78	8
Alaska	-	-	22.38	1

*Adapted from Provisional Patient Movement, 1967.

Table 4*

The Percentage of Each State's Resident Population

Falling in the Various Levels of Retardation During 1965

State	Borderline IQ 68-83	Mild IQ 51-67	Moderate IQ 36-50	Severe IQ 20-35	Profound IQ <20
Alabama	2	13	24	24	37
Arizona	2	12	25	25	36
Arkansas	13	20	25	25	17
California	2	14	25	32	25
Connecticut	7	20	19	22	32
Delaware		27	36	20	17
District of Columbia		21	48	18	13
Florida	6	14	23	25	32
Georgia	4	9	18	24	44
Hawaii		21	27	-52-	
Idaho	2	10	13	35	40
Illinois	6	18	27	12	37
Indiana	8	20	34	-38-	
Iowa	4	9	16	23	48
Kansas	4	11	18	32	34
Kentucky	5	12	21	39	24
Louisiana	6	10	16	26	42
Maryland	4	17	22	28	30
Massachusetts	8	14	28	36	14
Michigan	6	14	32	34	14
Minnesota	4	16	36	30	14
Mississippi	3	23	23	29	20
Missouri	5	18	19	42	16
Montana	3	26	33	28	10
Nebraska	8	23	29	31	10
Nevada			9	91	
New Hampshire		6	26	40	28
New Jersey	5	17	23	-55-	
New Mexico	1	17	28	34	20
New York	-31-		-52-		17
North Carolina	3	17	31	33	16
North Dakota	3	16	25	32	24
Ohio	6	22	25	24	22
Oklahoma	4	16	23	30	27
Oregon	12	14	17	19	39
Pennsylvania	6	13	27	31	21
Rhode Island	5	15	20	28	32
South Carolina	7	17	-51-		25
South Dakota	5	19	33	25	18
Tennessee	5	9	20	22	43
Texas	4	19	28	28	22
Utah	4	12	12	26	46
Vermont	3	20	30	27	20
Virginia	3	16	18	36	28
Washington	-25-		34	-41-	
West Virginia	2	11	17	23	47
Wisconsin	5	9	19	30	36
Wyoming	12	19	19	24	26

*Adapted from Milligan and Nisonger, 1965.

Table 5*

The Percentage of Each State's Admissions During 1965 Falling in the Various Levels of Retardation

State	Total Admitted	None	Borderline	Mild	Moderate	Severe	Profound	Unknown
Alabama	164	5	5	15	22	21	30	1
Arizona	61			13	26	20	25	16
Arkansas	106		7	19	31	34	9	
California	1,104	.36	1	12	22	34	29	2
Colorado	122		2	9	14	18	48	8
Connecticut	154	.65	17	36	18	8	16	3
Delaware	48			19	33	40		8
District of Columbia	81			31	43	26		
Florida	374	.27	8	12	20	20	33	7
Georgia	161		6	13	16	7	24	34
Hawaii	70		6	7	13	34	30	10
Indiana	286	.69	6	15	20	20	22	16
Iowa	145		6	18	27	17	30	2
Kansas	167		13	14	26	16	26	5
Kentucky	107		2	7	6	16	8	61
Maine	124	3	7	29	20	17	23	
Michigan	1,059	3	12	15	12	10	11	37
Mississippi	176	4	9	23	20	14	38	2
Missouri	203		2	2	7	7	6	75
Montana	56		7	23	25	32	13	
Nebraska	112		9	8	26	25	9	23
New Hampshire	61			13	31	56		
New Jersey	492	.61	4	11	12	23	15	35
New Mexico	103			14	33	30	20	3
New York	1,562	1	12	26	17	23	20	2
North Carolina	501	1	4	25	27	16	13	14
North Dakota	50		10	12	22	10		46

Table 5 (Cont.)

State	Total Admitted	None	Borderline	Mild	Moderate	Moderate	Profound	Unknown
Ohio	627	2	9	24	19	26	16	4
Oklahoma	670		2	6	24	32	35	1
Oregon	160	.63	9	13	11	11	21	33
Pennsylvania	887	.39	5	19	23	22	24	5
Rhode Island	19		5	21	5			68
South Dakota	49		2	24	14	29	31	
Tennessee	207	.48	3	7	18	26	44	2
Texas	1,249	.08	3	9	10	13	29	36
Utah	26		15	19	19	15	31	
Vermont	48		8	8	29	17	13	25
Virginia	401	1	11	21	18	10	12	26
Washington	226	1	4	20	23	19	8	25
West Virginia	114	2	.87	12	14	66	5	
Wisconsin	254	1	2	10	23	40	23	1
Wyoming	30	3	7	23	17	7	37	7

*Adapted from Patients in Mental Institutions, 1965.

Table 6*

1966 Daily Maintenance Expenditures in Institutions for the Mentally Retarded, by State and Number of Residents per 10,000 Population

State	Daily Maintenance Cost per Resident	Rank	Residents per 10,000 Pop.	Rank
Alaska	$22.38	1	-	-
Kansas	12.18	2	8.81	31
New Mexico	12.11	3	6.07	41
California	11.41	4	7.11	37
Rhode Island	10.64	5	10.56	20
Wisconsin	10.63	6	9.06	29
Connecticut	8.82	7	13.70	15
West Virginia	8.78	8	2.61	49
Maine	8.66	9	10.20	22
Colorado	8.55	10	10.01	24
Kentucky	8.44	11	3.46	47
Hawaii	8.31	12	12.17	16
Louisiana	8.23	13	6.36	40
Michigan	8.07	14	15.03	10
Oklahoma	8.05	15	8.43	33
Iowa	7.97	16	6.78	38
Maryland	7.72	17	8.43	32
Illinois	7.54	18	9.20	28
Georgia	7.47	19	4.37	46
Indiana	7.42	20	8.04	34
Washington	7.36	21	14.01	14
Florida	7.32	22	7.61	36
Delaware	7.17	23	11.45	18
Idaho	7.13	24	10.54	21
New Jersey	7.13	25	9.49	27
Pennsylvania	7.09	26	10.05	23
Arkansas	7.07	27	3.38	48
Oregon	7.02	28	14.79	12
New York	6.94	29	15.02	11
North Carolina	6.92	30	8.97	30
Massachusetts	6.69	31	16.09	8
District of Columbia	6.58	32	16.28	7
Wyoming	6.50	33	22.00	1
Missouri	6.36	34	5.70	42
Minnesota	5.95	35	15.34	9
Tennessee	5.92	36	5.39	45
Utah	5.86	37	10.94	19
Vermont	5.76	38	16.37	6
New Hampshire	5.60	39	16.76	4
Arizona	5.38	40	5.56	44
Ohio	5.08	41	9.71	25
Montana	5.00	42	14.73	13
Texas	4.88	43	9.61	26
Virginia	4.71	44	8.02	35
North Dakota	4.39	45	18.90	3
Alabama	4.04	46	6.45	39
South Carolina	3.90	47	11.82	17
Nebraska	3.58	48	16.45	5
South Dakota	3.17	49	19.33	2
Mississippi	2.30	50	5.62	43

*Adapted from Provisional Patient Movement, 1967.

Table 7*

Expenditures To Improve and To Maintain Public Institutions for the Retarded, by State, During 1965

State	Total Expenditures	Additions Improvements	Salaries Wages	Purchases	Fuel Lights	Other
New York	$80,557,050	22%	81%	9%	3%	7%
California	49,586,540	3	35	6	2	7
Michigan	36,451,142	9	83	10	3	4
Pennsylvania	28,035,718	4	74	9	5	12
Massachusetts	21,156,043		79	7	4	10
Ohio	19,810,085	9	77	10		14
Wisconsin	18,765,068	32	82	5	2	10
Texas	16,456,183	5	74	21	4	1
Indiana	13,442,220	31	72	11	4	13
New Jersey	13,045,388	3	77	9	4	11
Minnesota	11,782,016	.001	75	11	5	9
Florida	11,127,654	6	77	11	3	9
Washington	11,087,895	4	65	27	3	3
North Carolina	10,777,068	4	75	12	3	10
Connecticut	10,312,453	5	76	14	4	6
Kansas	9,500,610	11	79	15	3	4
Iowa	6,310,205	21	75	11	3	12
Oklahoma	5,981,417	4	72			28
Louisiana	5,875,178	12	80	13	4	4
Virginia	5,846,211	5	77	15	3	5
Colorado	5,593,058	2	82	11	3	4
Tennessee	5,402,876	26	61	17	4	18
Georgia	4,894,975	12	67	24	3	5
District of Columbia	3,780,990	8	86	8	3	3
Kentucky	3,379,896	9	70	7	5	18
Rhode Island	3,343,818	1	63	10	3	24
Nebraska	2,833,752	2	72	19	7	3
Alabama	2,656,424		64	10	3	23
New Hampshire	2,475,180	7	83	6	3	8
Hawaii	2,264,523	1	76	10	1	12
North Dakota	2,046,358	.007	73	7	4	16
Arkansas	1,845,122	35	69	23	4	5
Arizona	1,763,449	20	69	20	3	8
Idaho	1,659,253	5	77	4	3	16
Wyoming	1,626,803	17	68	11	3	18
South Dakota	1,620,508	7	69	10	6	15
Utah	1,616,110	2	71	10	2	17
New Mexico	1,601,688	10	69	17	4	11
Delaware	1,470,817	4	74	10	5	11
Montana	1,359,245	6	64	9	5	22
West Virginia	1,304,209	.003	68	19	4	9
Mississippi	1,261,328	3	52	14	4	30
Vermont	1,190,415	3	71	6	5	18
Alaska	162,100	9	63	10	5	21

*Adapted from Patients in Mental Institutions, 1965.

Table 8*

Average Daily Population and Number of Residents for Each Full Time Physician, Psychologist, Registered Nurse, Principal and Teacher, and Social Worker in Public Institutions for the Retarded During 1965

State	Average Daily Population	Attendant	Physician	Psychologist	Registered Nurse	Principal, Teacher	Social Worker
Alabama	2,145	6.11	429.00	715.00	178.70	112.80	536.20
Alaska	30	2.50			6.00		
Arizona	833	3.28	416.50	277.60	119.00	37.86	416.50
Arkansas	390	2.12	390.00	97.50	78.00	20.53	130.00
California	12,610	3.31	175.14	274.13	34.45	141.69	242.50
Colorado	1,873	3.03	312.17	187.30	60.42	49.29	187.30
Connecticut	3,720	3.72	465.00	310.00	128.28	44.82	248.00
Delaware	566	3.88	113.20	566.00	31.44	29.79	113.20
District of Columbia	1,167	4.04	233.40	233.40	61.42	50.74	291.75
Florida	4,063	2.26	270.87	312.54	51.43	66.61	253.94
Georgia	1,837	5.25	612.33	612.33	54.03	79.87	612.33
Hawaii	852	4.04	426.00	426.00	56.80	142.00	94.67
Idaho	732	4.33		732.00	91.50	91.50	366.00
Indiana	3,893	3.90	556.14	278.07	84.63	81.10	169.26
Iowa	2,204	4.39	169.54	137.75	146.93	66.79	122.44
Kansas	2,014	4.55	95.90	118.47	29.19	71.93	91.55
Kentucky	1,334	5.65	190.57	266.80	55.58	44.47	7.06
Louisiana	2,176	2.73	310.86	725.33	90.67	103.62	217.60
Maine	1,140	4.49	103.64	114.00	54.29	33.53	95.00
Massachusetts	8,953	4.22	172.17	389.26	56.31	73.99	298.43
Michigan	12,534	4.11	305.71	569.73	78.83	121.69	192.83
Minnesota	5,916	5.59	394.40	493.00	75.85	116.00	219.11
Mississippi	1,173	4.93	586.50	586.50	391.00	117.30	
Missouri	2,488	3.94	311.00	829.33	113.09	207.33	207.33
Montana	914	6.53	914.00	914.00	114.25	91.40	914.00

Table 8 (Cont.)

State	Average Daily Population	Attendant	Physician	Psychologist	Registered Nurse	Principal, Teacher	Social Worker
Nebraska	2,299	5.94	574.75	2,299.00	287.38	127.72	574.75
New Hampshire	971	3.93	323.67	242.75	74.69	88.27	323.67
New Jersey	5,856	3.95	366.00	344.47	66.55	57.41	585.60
New Mexico	514	2.61	514.00	128.50	64.25	36.71	171.33
New York	26,794	4.12	212.65	1,488.55	73.61	92.08	461.97
North Carolina	4,543	3.54	216.33	908.60	52.83	51.63	189.29
North Dakota	1,358	5.20	452.67	679.00	452.67	150.89	452.67
Ohio	10,113	4.92	439.70	632.06	153.23	106.45	374.56
Oklahoma	2,419	3.09	302.38	483.80	86.39	109.95	71.15
Pennsylvania	11,460	4.63	347.27	369.68	42.60	136.43	229.20
Rhode Island	988	3.74	247.00	329.33	61.75	49.40	109.78
South Dakota	1,215	5.45	405.00	607.50	303.75	101.25	
Tennessee	1,998	4.30	222.00	222.00	133.20	153.69	222.00
Texas	10,051	4.34	346.59	502.55	239.31	201.02	502.55
Utah	864	4.97			864.00	78.55	432.00
Vermont	663	5.10	663.00	663.00	110.50	94.71	221.00
Virginia	3,408	4.82	243.43	486.86	69.55	83.12	243.43
Washington	3,998	4.31	266.53	399.80	70.14	499.75	133.27
West Virginia	475	2.42	237.50		39.58	475.00	237.50
Wisconsin	3,779	3.27	314.92	944.75	35.99	77.12	139.96
Wyoming	624	4.62	156.00	124.80	124.80	69.33	208.00

*Adapted from Patients in Mental Institutions, 1965.

Nearly half of the states have only one institution for the retarded, and it, of necessity, serves many purposes. Even in those states with more than one institution, the majority are large multipurpose facilities. Over half of the public institutions in this country house more than 1,000 residents. They try to meet the differing needs of the mildly and the profoundly retarded, the physically normal and active as well as the bed-ridden, the young and the aged, the rebellious delinquent as well as the docile, etc.

Despite this general preponderance of large, multi-purposed institutions, a trend has recently developed for institutions to be built for fewer residents. Thus, three-fourths of the public institutions built since 1960 are intended for 500 or fewer residents. Some states, for example Connecticut, Missouri, and Texas, are actively committed to this plan of building many smaller institutions, while others appear to be continuing with the older pattern of building large facilities.

Six years ago when the President's Panel on Mental Retardation was deliberating, many of the kinds of facts which were readily assembled for this report were obtained with only the greatest difficulty. The reporting of institutional census and cost information has been improved greatly in the last 6 years. Now the pathetic lack is in objective information about the effects of institutions upon the retarded. In view of the facts about the character of public institutions, it is easy to assume that their effects are largely negative. But there is a need to know precisely how negative they are, and in what ways, in order to most wisely plan their improvement. It is to be hoped that the next few years will see not only the elimination of deplorable conditions within our institutions but also an accumulation of information about the effects of institutionalization comparable to the accumulation of census and cost information of the last few years.

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Part III: Reactions to Current Residential Models In the United States

Chapter 3

Purgatory

Burton Blatt

Massachusetts Department of Mental Health

PURGATORY[1]

"All hope abandon, ye who enter here."--Dante

With a good deal of anxiety, I waited for the white-uniformed attendant to respond to my knocking and unlock the door to Hell. And in America, we have our own special Inferno. I was a visitor there during the Christmas season, 1965, while studying five state institutions for the mentally retarded, located in four Eastern states.

As I awaited entrance to the above-mentioned building, which was a residential dormitory, my anxiety belied the ostensible situation. In the 18 years that I had been professionally active in the field of mental retardation, I had been to scores of institutions. I had served on numerous commissions to evaluate or advise such institutions. In fact, the building I was about to enter--and which terrified me now--was no stranger to me. Over the years, and for one reason or another, I had found it necessary to visit this building, never giving it any particular thought; one might say I had visited it thoughtlessly.

However, my fears were not the neurotic outcroppings of an unhinged mind. I had a great deal to be worried about and, during the few moments I waited for entrance to this dormitory, my thoughts flashed back to those antecedents that brought me here. In the early fall of 1965, Senator Robert Kennedy visited several of his state's institutions for the mentally retarded. His reactions were widely published in our various news media, shocking millions of Americans as well as infuriating scores of public officeholders and professional persons responsible for the care and treatment of the mentally retarded. Most of the laymen with whom I discussed his visits reacted to the Senator's disclosures with incredulity. For it is difficult for "uninvolved" people to believe that, in our country, and at this time, human beings are being treated less humanly and under more deplorable conditions than are animals. A number of the "involved" citizenry, i.e., those who legislate and budget for institutions for the mentally retarded and those who administer them, were infuriated because the Senator reported only the worst of what he had seen, not mentioning the worthwhile programs that he undoubtedly was shown. Further, this latter group was severely critical of the Senator for taking "whirlwind" tours and, in the light of just a few hours of observation, damning entire institutions and philosophies.

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[1] This work is part of a chapter of the author's forthcoming book, Exodus From Pandemonia. It was written during the summer of 1966 for Look. As a result of the severe space limitations, a very modest fraction eventually appeared in that magazine. The author believes that his work represents a more complete discussion of his story Christmas in Purgatory as it pertains to the so-called back wards.

During the time of these visits, I was a participant in a research project at The Seaside, a State of Connecticut regional center for the mentally retarded. The superintendent of The Seaside, Fred Finn, and I spent a considerable amount of time discussing, in particular, the debate between Senator Kennedy and New York Governor Nelson Rockefeller. We concluded the following: it does not require a scientific background or a great deal of observation to determine that one has entered the "land of the living dead"; it does not require too imaginative a mind or too sensitive a nose to realize that one has stumbled onto a dung hill, whether or not, as Cervantes wrote, it is covered with a piece of tapestry when a procession (of distinguished visitors) goes by; it is quite irrelevant how well the rest of an institution's program is being fulfilled if one is concerned with that part of it which is terrifying. No amount of rationalization can mitigate that which, to many of us, is cruel and inhumane treatment.

It is true that a short visit to the back wards (the hidden, publically unvisited living quarters) of an institution for the mentally retarded will not provide, even for the most astute observer, any clear notion of the causes of the problems observed, the complexities of dealing with them, of ways to correct them. It is not difficult to believe that Senator Kennedy could not fully comprehend the subtleties, the tenuous relationships, the grossness of budgetary inequities, the long history of political machinations, the extraordinary difficulty in providing care for severely mentally retarded patients, the unavailability of highly trained professional leaders, and the near-impossibility in recruiting dedicated attendants and ward personnel. Further, I do not believe the conditions Senator Kennedy claimed to have observed were due to evil people. As Seymour Sarason, Professor of Psychology at Yale University, wrote in the preface to our book (*Christmas in Purgatory: A Photographic Essay on Mental Retardation*. Boston: Allyn and Bacon, 1967), these conditions are "...not due to evil or incompetent or cruel people but rather to a conception of human potential and an attitude toward innovation which when applied to the mentally defective, result in a self-fulfilling prophecy. That is, if one thinks that defective children are almost beyond help, one acts toward them in ways which then confirm one's assumptions."

However, regardless of their antecedents, I believe, as well as do thousands of others who have been associated with institutions for the mentally retarded, that what Senator Kennedy reported he saw he very likely did see. In fact, I know personally of few institutions for the mentally retarded in the United States that are completely free of dirt and filth, odors, naked patients groveling in their own feces, children in restraints and in locked cells, horribly crowded dormitories, and understaffed and wrongly staffed facilities.

After a good deal of thought, I decided to follow through on what then seemed, and what eventually became, a bizarre venture. One of my friends, Fred Kaplan, is a professional photographer. On Thanksgiving Day, 1965, I presented the following plan to him. We were to arrange to meet with each of several key administrative persons in a variety of public institutions for the mentally retarded. If we gained an individual's cooperation, we would be taken on a "tour" of the back wards and those parts of the institution that he was most ashamed of. On the "tour" Fred Kaplan would take pictures of what we observed, utilizing a hidden camera attached to his belt.

Through the efforts of courageous and humanitarian colleagues, including two superintendents who put their reputations and professional positions in jeopardy, we were able to visit the darkest corridors and vestibules that humanity provides for its "journey to purgatory," and, without being detected by ward personnel and professional staff, Fred Kaplan was able to take hundreds of photographs.

Our photographs were not always the clearest. On the other hand, it required a truly creative photographer to be able to take these pictures, "from the hip" so to speak, unable to use special lighting, not permitted to focus or set shutter speeds, with a small camera concealed in multitudes of clothing and surrounded by innumerable "eyes" of patients as well as of staff. Although our pictures cannot even begin to capture the total and overwhelming horror we saw, smelled, and felt, they represent a side of America that has rarely, if ever, been shown to the general public and is little understood by most of the rest of us.

I do not believe it is necessary to disclose the names of the institutions we visited. First, to reveal those names is assuredly an invitation to the dismissal of those who arranged for us to photograph their deepest and most embarrassing "secrets." However, involved, is not only a matter of promises made to altruistic people but avoidance of the impression that the problems now exposed are local rather than national ones. I am completely convinced that in numerous other institutions across America I can observe similar conditions--some, I am sure, even more frightening.

Had I known what I would actually be getting myself into and had I known what abnormal pressures would subsequently be exerted upon me as a result of this story and my efforts to bring it before the American people, I might have turned away from that first dormitory entrance as I was, finally, being admitted; and I might have fled to the shelter and protection of my academic "ivory tower" to ruminate on the injustices prevailing in society. Although I did not expect this to be a pleasurable study, I was in no way prepared for the degradation and despair I encountered, experiences which caused me to develop a chronic sorrow, one that will not abate until the American people are aware of--and do something about--the treatment of certain mentally retarded human beings in our state institutions.

As I entered this dormitory, housing severely mentally retarded adolescents and adults, I was still reminiscing about Senator Kennedy, Governor Rockefeller, and our fateful Thanksgiving dinner until, almost immediately after I passed the threshold, an overwhelming stench enveloped me. It was the sickening, suffocating smell of feces and urine, decay, dirt and filth, of such strength as to hang in the air and, I thought then and am still not dissuaded, solid enough to be cut or shoveled away. But, as things turned out, the odors were among the gentlest assaults on my sensibilities. I was soon to learn about the decaying humanity that caused them. This story--my purgatory in black and white--which, ironically, was conceived, of and written on the 700th anniversary of the birth of Dante, represents my composite impressions of what I consider to be the prevailing conditions of certain sectors of most institutions for the mentally retarded in this country. It is in the hope of calling attention to the desperate needs of these institutions, and thereby, paving the way for upgrading all institutions for the mentally retarded in all dimensions of their responsibilities that this study was undertaken and this story written.

Several things strike a visitor to most institutions for the mentally retarded upon his arrival on the institution grounds. Sometimes there are fences, once in a while with barbed wire. Very frequently the buildings impress him with their sheer massiveness and impenetrability. I have observed bars on windows and locks--many locks--on inside as well as outside doors. As I entered the dormitories and other buildings, I was impressed with the functional superiority of the new building but, on the other hand, with the gross neglect in many of the older ones. I have observed gaping holes in ceilings of such vital areas as the main kitchen. In toilets, I frequently saw urinals ripped out, sinks broken, and the toilet bowls backed up. In every institution I visited, with the exception of The Seaside, I found incredible overcrowding. Beds are so arranged--side by side and head to head--that it is impossible, in some dormitories, to cross parts of the rooms without actually walking over beds; oftentimes the beds are without pillows. I have seen mattresses so sagged by the weight of the bodies that they were scraping the floor.

Before I go further, it would be well to point out a crucial factor giving rise to the overcrowdedness, the disrepair of older buildings, the excessive need for locks and heavy doors, and the enormity of buildings and the numbers of patients assigned to dormitories. About 200,000 adults and children currently reside in public institutions for the retarded in this country, at a cost of about $500,000,000 a year in operating expense alone. At first glance, this appears to be a great deal of money and, to the unknowing laymen, is cause for comfort, i.e., the mentally retarded have finally received their due. However, simple arithmetic tells us that $500,000,000 divided by 200,000 amounts to $2,500 a year, or about $48 per week or $7 per day. This is about one-eigth the amount spent for a day's general hospital care. Four states spent less than $4 per day in 1966. In some checking that I have done recently, I learned that in our better zoos, the larger animals require a higher per capita expenditure.

The average per capita daily cost for maintaining a retarded resident in each of the four institutions I described was, at that time, less than $7, in one case less than $5. In contrast, The Seaside, a new regional center for the retarded, sponsored by the Connecticut Department of Health and discussed in our aforementioned book Christmas in Purgatory, spent $12 daily for care and treatment of each resident. Although it may be true that money corrupts, it may be equally true that its absence is similarly corrupting.

> "Inasmuch as ye have done it unto one
> of the least of these my brethren, ye
> have done it unto me."--Matthew 25:40.

All of the doors in institutional buildings visited that are used as living quarters for young children, and moderately and severely retarded residents of any age, have locks. These locks are on all outside doors as well as all inside doors. Many of the doors are made of heavy gauge metal or thick wood. All of the locks appear to be formidable, and it is routine, second nature, for attendants to pass from room to room with a key chain in hand unlocking and locking doors en route.

Many dormitories for the severely and moderately retarded ambulatory residents have solitary confinement cells or, what is officially referred to and is jokingly called by many attendants , "therapeutic isolation." "Therapeutic isolation" means solitary confinement--in its most punitive and inhumane form. These cells are usually located on an upper floor, off to the side and away from the casual or official visitor's scrutiny. (Coincidentally, a United States Senator had visited a dormitory at a state institution 3 days prior to one of my visits there. In discussing this with him weeks later, I showed him pictures taken of solitary confinement cells in that dormitory. As one might expect, he had not been shown these cells during his tour and, I believe it possible, he was not absolutely sure that I did not concoct this coincidence to impress upon him the urgency of my mission.) Isolation cells are generally tiny rooms, approximately 7 feet by 7 feet, shielded from the outside with a very heavy metal door having either a fine strong screen or metal bars for observation of the "prisoner." Some cells have mattresses, others blankets, still others bare floors. None that I had seen (and I found these cells in each institution visited) had either a bed, a wash stand, or a toilet. What I did find in one cell was a 13- or 14-year-old boy, nude, in a corner of a starkly bare room, lying on his own urine and feces. The boy had been in solitary confinement for several days for committing an institutional infraction, as I recall, directing abusive language to an attendant. Another child, in another institution, had been in solitary confinement for approximately 5 days for breaking windows. Another had been in isolation, through a long holiday weekend, because he had struck an attendant. Ironically, in the dormitory where this boy was being incarcerated, I saw another young man who had been "sent to bed early" because he had bitten off the ear of a patient several hours previously. Apparently, it is infinitely more serious to strike an attendant (and it should not be misunderstood that I condone this) than to bite off the ear of another resident.

In one institution I saw a young man who was glaring at me through the screen of the door in the solitary cell, feces splattered around this opening. He, too, was being punished for breaking an institutional regulation. In this particular dormitory, I had a good opportunity to interview the attendant in charge. I asked him what he needed most in order to better supervise the residents and provide them with a more adequate program. The attendant's major request was for the addition of two more solitary confinement cells, to be built adjacent to the existing two cells that, I was told, were always occupied, around the clock, day in and day out. Unfortunately, I have recent confirmation of the constant use of the solitary cells. Seven months after the above-mentioned incident I revisited this dormitory. Both solitary confinement cells were occupied, and there was a waiting list for other youngsters who were to receive this punishment.

I saw a great deal of restraints used with children. I observed many children whose hands were tied, legs bound, or waists secured. After a good deal of discussion with a number of attendants and supervisors in the four institutions, I was convinced that one of the major reasons for the frequent use of solitary confinement and physical restraints was the extraordinary shortage of staff in practically all of these dormitories. The attendant who requested the construction of two additional solitary confinement cells was, with one assistant, responsible for the supervision of an old multilevel dormitory, housing over a hundred severely retarded ambulatory residents. Almost in desperation he asked me, "What can one do with those patients who do not conform? We must lock them up, or restrain them, or sedate them, or put fear into them." At that point, I did not feel I had a response that would satisfy either him or me. I suffered in silence in much the same way, I imagine, men of conscience suffered upon reading Reil's description in 1803 of institutional problems that were astonishingly similar to those I encountered. He said then, "We lock these unfortunate creatures in lunatic cells, as if they were criminals. We keep them in chains in forlorn jails. . . where no sympathetic human being can ever bestow them a friendly glance, and we let them rot in their own filth. Their fetters scrape the flesh from their bones, and their wan, hollow faces search for the grave that their wailing and our ignominy conceals from them." My thoughts went back to that anonymous writer who, in 1795, said: "A humanitarian is bound to shudder when he discovers the plight of the unfortunate victims of this dreadful afflication; many of them grovel in their own filth on unclean straw that is seldom changed, often stark naked and in chains, in dark, damp dungeons where no breath of fresh air can enter. Under such terrifying conditions, it would be easier for the most rational person to become insane than for a mad man to regain his sanity."

"I sometimes hold it half a sin to
put in words the grief I feel."--
Alfred, Lord Tennyson.

In each of the dormitories for severely retarded residents there is what is called, euphemistically, the dayroom or recreation room. The odor in each of these rooms is overpowering, to the degree that after a visit to a dayroom I had to send my clothes to the dry cleaners in order to have the stench removed (and, probably because of psychological reactions, whose odor I continued to smell months later whenever I wore certain clothes). The physical facilities often contributed to the visual horror as well as to the odor. Floors are sometimes made of wood and, as a result, excretions are rubbed into the cracks, thus providing a permanent aroma. Most dayrooms have a series of bleacherlike benches on which sit denuded residents, jammed together, without purposeful activity or communication or any kind of interaction. In each dayroom is an attendant or two, whose main function seems to be to "stand around" and, on occasion, hose down the floor, "driving" excretions into a sewer conveniently located in the center of the room.

I was invited into female as well as male dayrooms, in spite of the supervisor's knowledge that I, a male visitor, would be observing denuded females. In one such dormitory, with an overwhelming odor, I noticed feces on the wooden ceilings, and on the patients as well as the floors.

Early in the evening, sometimes at 5 o'clock, patients are put to bed. This is to equalize the workload among the different shifts. During the day, I saw many patients lying on their beds, apparently for long periods of time. This was their activity. During these observations, I thought a good deal about the perennial cry for attendants and volunteer workers who are more sympathetic and understanding of institutionalized retarded residents. One of the things I realized was that attendants might be sympathetic, might interact more with patients, if institutional administrators made deliberate attempts to make patients cosmetically more appealing. For example, adult male residents should shave, or be shaven, more than once or twice a week. Dentures should be provided for any patient who needs them. It seems plausible to believe that it is much more possible to make residents more attractive and, therefore, more interesting to attendants than it is to attempt to convince attendants that they should enjoy the spectacle of unwashed, unkept, odoriferous, toothless old men and women.

"My friends forsake me like
a memory lost."--John Clare.

The living quarters for older men and women were, for the most part, gloomy and sterile. There were rows and rows of benches on which sat countless human beings, in silent rooms, waiting for dinner call or bedtime. I saw resident after resident in "institutional garb."

Sometimes, the women wore shrouds--inside out. I heard a good deal of laughter but saw little cheer. There were few things to be cheerful about. A great many of the men and women looked depressed and acted depressed. Even the television sets, in several of the dayrooms, appeared to be co-conspirators in a crusade for gloom. These sets were not in working order, although, ironically, the residents continued to sit on their benches, in neat rows, looking at the blank tubes. I observed adult residents during recreation playing Ring-Around-The-Rosy. Others, in the vocational training center, were playing Jacks. These were not always severely retarded patients. However, one got the feeling very quickly that this is the way they were being forced to behave. Or, as Hungerford said, ". . . in an institution there is always tomorrow so that he who starts out a student ends up, by default, an inmate." Lastly, I viewed old women and very young girls in the same dormitories and old men and young boys as comrades in the dayroom. In the "normal" world, there is something appealing, even touching, about such friendships; in the institution, there is something opportunistic, sinister, and ludicrous.

"Suffer the little children..."

The children's dormitories depressed me the most. Here, cribs were placed, as in the other dormitories, side by side and head to head. Very young children, one and two years of age, were lying in cribs without contact with any adult, without playthings, without apparent stimulation. In one dormitory that had over 100 infants and was connected to nine other dormitories that totalled 1,000 infants, I experienced my deepest sadness. As I entered, I heard a muffled sound emanating from the "blind" side of a doorway. A young child was calling, "Come, come play with me. Touch me." I walked to the door. One the other side were 40 or more unkept infants crawling around a bare floor in a bare room. One of the children had managed to squeeze his hand under the doorway and push his face through the side of the latched door and was crying for attention. His moan begged me for some kind of human interaction.

In other dayrooms I saw groups of 20 or 30 very young children lying, rocking, sleeping, sitting--alone. Each of these rooms was without doors or adult human contact, although each had desperate-looking adult attendants "standing by."

During my visit to the institution, I was told about the development of a new research center on the institutional grounds. The assistant superintendent mentioned to me that the "materials" for the research center would come from the institution and this center would require the addition of approximately 30 or 40 "items." I was quite confused by this statement and, as a result of some verbal fumbling and embarrassment, I finally did understand what was being said to me. At that institution, and apparently at others in that state, patients are called "material" and personnel are called "items." It was so difficult not to believe that this assistant superintendent was either "pulling my leg" or using some idiosyncratic jargon that during my subsequent visits to dormitories in that institution I asked the attending physicians, "How many 'items' do you have in this building? How much 'material' do you have?" To my amazement, they knew exactly what I was asking for and gave me the numbers immediately.

In another dormitory, I was taken on a tour by the chief physician, who was anxious to show me a child who had a very rare condition. The doctor explained to me that, aside from the child's dwarfism and misshapen body, one of the primary methods for diagnosing this condition is the deep guttural voice. In order to demonstrate this, he pinched the child. The child did not make any sound. He pinched her again, and again--harder and still harder. Finally, he insured her response with a pinch that turned into a gouge and caused the child to scream, in obvious pain.

In some of the children's dormitories I observed "nursery programs." What surprised me most was their scarcity and, unfortunately, the primitiveness of those in operation. Therefore, I was not unprepared to see several children with severe head lacerations. I was told these were the "head bangers." Head banging is another condition that some people think is inevitable when confronted with young, severely mentally retarded children. I challenge this. I have reason to believe that head banging can be drastically reduced in an environment where children have other things to do. Alice Metzner once said, "There are only two things wrong with most special education for the mentally handicapped, it isn't special, and it isn't education." From my observation of the "nursery programs" conducted at the state schools visited, I would have to agree with the second part of Miss Metzner's complaint. The special education I observed at the state schools bore no resemblance to what I would consider to be "education." But, it was special. It was a collection of the most depressing "learning" environments I have ever had the misfortune to witness. But, as Hungerford also said, "Time buries the mistakes of many school programs."

> "One may find his religion
> in the clinical setting."
> --Albert T. Murphy.

I have learned a great deal during my visits to these institutions. I have learned about the treatment of the severely mentally retarded, and all young children, who are institutionalized. But, essentially, and possibly most importantly, I have learned something about the dominating factor that influences man in his treatment of other human beings. And this is a concept that is worth striving to understand. No doubt the reader of this piece has asked himself several times, "Why do attendants and supervisors treat mentally retarded patients the way this author presents the situation to be?" It is probably imcomprehensible to you to believe that such conditions exist. Because of my years in observing these affairs, I may have been a little further along the way in rationalizing and, to my shame, accepting them. That is to say, I knew with certainty that these conditions existed. However, I was about as puzzled as anyone else in explaining why we permit them to continue. Now I may have a glimmer of enlightenment that I want to share with you.

It has always intrigued me to think about why antivivisectionists are so passionate in their beliefs concerning the use of animals for scientific experimentation. To me, animals have always been creatures to enjoy, to act kindly toward, and not to inflict any unnecessary punishment on. I believe this is they way most thoughtful human beings view the animal kingdom. I think of myself as a reasonable man. I have no interest--in fact I have revulsion--in inflicting unnecessary pain on any creature. However, I would be less than candid if I did not admit that stories about carefully controlled, and apparently necessary, animal experimentation never offend me. Further, I have never really lost any sleep or had any sustained grief in hearing about or observing cruelty to animals. I do not enjoy such spectacles. On the other hand, I have never been motivated enough to directly intervene to prevent them. However, there are people, some of our closest friends, who cry real tears and display deep emotions when confronted with cruelty to animals. During this study I began to understand, finally, why antivivisectionists are the way they are and why I am so different. Further, I began to understand how human beings can be treated so dispassionately and cruelly in institutions. Antivivisectionists must conceive of animals in ways other people conceive of human beings. If you look at the antivivisectionists in this light, it is not difficult to understand their anguish in observing inhuman behavior to animals. On the other hand, certain human beings have been taught or trained--or this is part of their nature--to conceive of other human beings in ways that most of us think of animals. If this is so, it is not difficult to understand why, and how, institutional attendants and their supervisors can treat the mentally retarded in the ways they do. It is not that these attendants are cruel or incompetent people--although, all too often, they are--but they have come to believe, for various reasons, that those in their charge are not really human. The words that are used in institutions describing certain mentally retarded residents give substance to my notion. When one views a group of human beings in an official kind of way as "material," an increased per capita expenditre for resident care and additional staff is not sufficient alone to bring about the massive changes in institutional treatment that are necessary. The use of such terms as "basket case," "vegtable," and others too offensive to record here indicates that the basic problem to be surmounted before state institutions for the mentally retarded will change substantially lies in the realm of our conception about human behavior and its amenability to change. Or, as Sarason has said:". . . When one looks over the history of man the most distinguishing characteristic of his development is the degree to which man has underestimated the potentialities of men." Whatever ways we implement a program to reconstruct the philosophy and practices of institutions for the mentally retarded, our most forceful thrust must be in our attempts to reconceptualize our understanding of the nature and prerogatives of man. More important than the desperately needed increased per capita expenditure for institutional care, more important than the obvious necessity to reduce the size of institutions, more important than the alleviation of the now hopeless crowdedness of most institutions, is the necessity for infusing a fundamental belief among all who work with the mentally retarded that each of these individuals is equally human, not equally intellectually able, not equally physically appealing, but equally human beings. Carl Sandburg stated this much more eloquently than I could: "There is only one man in the world: and his name is ALL MEN."

Afterthoughts

It is many months since I have visited the institutions described here. During that time I have shown and discussed this story with a formidable, very heterogeneous but carefully selected, number of individuals. Their backgrounds range from those in very high public office to undergraduate college students preparing as special class teachers. The sentiments of the aforementioned individuals, and others too numerous to mention, convinced me that this story must be brought to the American people as speedily as possible. In discussing this work with my colleagues, I have been able to resolve some of my anxieties insofar as the possible adverse consequences of publication of this story. Further, I have been able to finally conceptualize a plan (presented later in this monograph) that might correct those antecedent conditions that led to the horror I observed.

The major questions that dictated caution and painful deliberation before a thoughtful answer could be found concerned themselves with whether or not this work represented an invasion of privacy of certain individuals, on the one hand, and whether the general public has a right to be protected from the knowledge of degradation, on the other. Insofar as the first matter, invasion of privacy, is concerned, I must question privacy on moral grounds. I believe that the so-called privacy of the back wards of these institutions contributes to suffering, for outsiders do not know the conditions within these buildings and, therefore, do little or nothing to promote improvements. When privacy contributes to suffering, it loses its significance as a cherished privilege. For those who could so reason, I do not believe that there would be many in the institutions who would object to my exposure of these frightening conditions if such exposure offered some possibility for a better life and chance for the residents. Lastly, as I discussed this issue with a number of people, I began to wonder whose privacies were being protected, institutionalized residents or the rest of us?

This leads to the second consideration. Do people have a right to know, whether they request this knowledge or not, the unvarnished nature of human activity? In order to avoid hysterical reactions to this study, I have deliberately shied away from comparisons of what I have seen with what took place in another country, with other kinds of human beings, toward the solution of other problems. I do not want to, in any way, leave the impression that what goes on in American state institutions for the mentally retarded is, by administrative design, barbaric, inhumane, or callous. However, I see certain obvious major problems, not the least being the general public's unawareness of conditions in our back wards.

The American people have the right to know. In spite of what we wish to know, in spite of the pain that knowing may bring to us, we have the right to be informed about any serious conditions that affect the human condition. There is a maturity that comes to a people when it no longer needs the protection of ignorance and, thus, of ignoring what needs to be attended to. Only very young children, with their fantasies, or sick adults, with theirs, believe that ignoring a problem can make it go away.

Postscript

One thousand copies of *Christmas in Purgatory* were published and distributed during the summer of 1966, without cost, to prominent legislators, commissioners of mental health, university professors, and leaders of the parent movement in mental retardation. It is not necessary here to discuss the flood of extraordinarily encouraging mail and calls I have received in response to this first edition of our book. It may be instructive to mention some of the negative, or otherwise puzzling, comments and hectoring that came to me.

One well-intentioned clergyman believes that I exhibited bad taste in reproducing photographs of nude men and women. An acquaintance in our field thinks of our work as a fake, the immoral use of a concealed camera comparing the atypical worst I had seen with "posed pictures" theatrically staged at The Seaside. A wise and beloved Commissioner of Mental Health asked me whether these conditions exist in his state's institutions. (How can I tell him about something he, as the principal responsible officer, should be aware of--and doing something about?) In another state that I have deep feeling for, a legislator who has championed mental health legislation circulated copies of *Christmas in Purgatory*, in the vain hope that it would help in the passage of social welfare legislation. He received scant support from his own party, who did not want the "opposition governor" to gain stature through such legislation in this an election year. The bill appeared doomed for many weeks, but subsequently passed, owing, I have been informed, in some part to the influence of our book.

I have just finished rereading C.P. Snow's two great essays on "The Two Cultures and the Scientific Revolution," in which he presents compelling arguments for viewing with alarm the completely separate paths trod by literary intellectuals and scientists. After reflecting on Snow's thoughts, one would have to be slow indeed not to realize the threat posed to society when two powerful cultures cannot or do not communicate and are often working at what appear to be cross purposes. However, there is another, far greater, danger to society!

For better and worse, the literary and artistic crowd and the scientists both have secure and powerful roles in our civilization. Will there ever be a day for the "literal" humanist? Is it the fate of mankind--for this is his history--to deny our human relatedness and the goodness that can come from it? We have all been, in our time, strangers in the land of Egypt and, consequently, must not willfully wrong any stranger--for he is our brother.

Albert Camus wrote, "Again and again there comes a time in history when the man who cares to say that two and two make four is punished with death." I have written the truth, as plainly and as simply as I see it--not for money or fame, for there has been very little of either connected with this assignment and there has been a good deal of grief. I would be surprised if this work changes radically the nature of institutions. My current depression will not permit such grand thoughts. On the other hand, as Camus wrote further, "Perhaps we can't stop the world from being one in which children are tortured but we can reduce the number of tortured children."

In spite of those who protest this presentation, there will be no turning back; the truth can no longer be concealed. Some good must come from all this pain and anguish to so many institutionalized residents and their families. Once seeds are sown, one only has to wait for the crop to harvest. It has also been said that, when the bellman is dead, the wind will toll the bell.

So hurry, wind! Or revive yourselves, noble bellringers.

Part III: Reactions to Current Residential Models in the United States

Chapter 4

A Scandinavian Visitor Looks at U.S. Institutions

Bengt Nirje
Swedish Association for Retarded Children

A SCANDINAVIAN VISITOR LOOKS AT U.S. INSTITUTIONS

"to believe you are born with bad luck though you are merely born" —Erik Lindegren, from "The Man Without A Way" (Mannen utan Vag), 1942.[1]

Foreign visitors to the United States are likely to be impressed by the seemingly inexhaustible resources and wealth of America. Thus, a visitor who works in the field of mental retardation in another country would be inclined to expect that public institutions for the retarded are planned, constructed, and operated with the same thoroughness and lavish disregard for cost that appear evident in the planning, construction and operation of other facilities such as expressways, motels, hotels, skyscrapers. A visitor with such expectations is in for a rude shock.

In the last 2 years, I have visited a number of public institutions in several states, and on each occasion I have reacted with disbelief and bewilderment to what I saw. I found it difficult to understand how a society which is built on such noble principles, and which has the resources to make these principles a reality, can and will tolerate the dehumanization of a large number of its citizens in a fashion somewhat remindful of Nazi concentration camps.

Since my first visit to the United States I have seen the book by Burton Blatt and Fred Kaplan (Christmas in Purgatory. Rockleigh, New Jersey: Allyn & Bacon, 1967) in which the conditions I have alluded to above were described and pictorially shown. Actually, I can add relatively little to this description except to say that my observations are similar to those of Blatt and Kaplan. I must, however, take exception to the use of the word "Purgatory," and not merely because I observed worse things than those depicted by the hidden and horrified camera at work in that too-little-known book. Once upon heathen times, there was an image of the god Moloch, an iron sculpture of a man, hollow, and made to be heated as a furnace. In the outstretched arms of this horrifying image of iron and fire, children were placed to be sacrificed for shallow reasons. Upon signals of the officiating witch-doctors and priest, the agonizing and sorrowful screams of the parents were solemnly and respectably drenched by the sound of trumpets and kettledrums. The image was placed deep down in a little valley 200 yards below what later was called Mount Zion. This place was named the Valley of Hinnom—thus giving the name to Gehenna, and later in slightly more enlightened times, to Hell.

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[1] Erik Lindegren, who died in 1968, was a major Swedish poet of the 20th century and a close personal friend of the author (Eds.).

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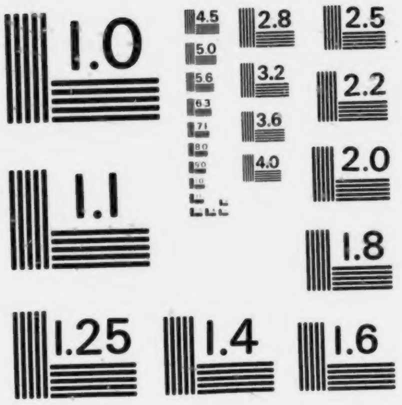
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MICROCOPY RESOLUTION TEST CHART
NATIONAL BUREAU OF STANDARDS-1963-A

Below, I will briefly sketch some of my observations. Upon entering a certain building of Institution No. 1 in the North-Central state M, personnel could be seen supervising, through a glass wall, a huge L-shaped dayroom, each wing of which was about 20 yards long and 10 yards wide. The bottom of the windows of this room was at eye-level for an adult. On the large terrazzo floor were a few wooden tables and benches and a couple of metal carrousels. In this dayroom no toys were to be seen. Some of the children had their heads lying across the tables; others huddled on the floor along the walls, or in the darkest corners if they could. This was the only dayroom for the severely retarded residents of this building. The adjoining room was their bedroom, with 87 beds in endless lines. About 10 children were lying in bed, some with excrement in their hands and mouth. Only one person was working with the children, and she was a mentally retarded girl about 16 years of age. The majority of the children spent only a few hours each day outside the building for recreation or for training purposes.

In the special hospital unit for low-functioning children with medical complications, I found several children tied to their beds, with plastic nose-feeding tubes constantly fastened to their noses and hanging over the high bars of their cribs.

In another and new building at Institution No. 1, moderately retarded girls of ages 10 to 16 were housed. Most of these girls apparently attended a training program, but 40 of them slept in the same bedroom, and the huge dayroom was equipped with only a few benches and a TV set. This created a deadening atmosphere for the girls upon their return from classes or recreation.

Another building at Institution No. 1 consisted of two large dayrooms, one dining hall, and a large single dormitory with 104 beds for severely and profoundly retarded adult men; large unsheltered toilets, without doors, opened directly into the dayrooms; the dayrooms, also without doors, opened into the bedroom. Since many residents were incontinent, a huge ventilation system had been installed on high legs at one end of the dormitory to eliminate most of the odors. At the side of the dormitory were isolation cells for residents engaging in destructive and disturbed behavior. Each cell was equipped with a toilet and a wooden chair. On the floor of one cell, a naked man was squeezing his own excrement. I was informed that the number of attendants on this ward for 104 men was a maximum of three, and often only one. The number of chairs was not sufficient for the number of residents, and most of the men who were not sitting were walking aimlessly around, some naked, some half-dressed in very simple clothes. Few residents of this building leave the building or its fenced-in outdoor exercise areas.

One hundred twelve profoundly and severely retarded children, ages 5 to 12, lived in a building at Institution No. 2 in state N. Some had physical disabilities, and a few were bedridden. The children lived in dormitories with 23, 44, and 45 beds respectively; they had one large terrazzoed dayroom with about 30 to 40 chairs and one TV set. Most of the children received occupational therapy on the bottom floor of the building once a day, aided by two therapists. The personnel consisted of 28 persons during a 24-hour period, with 9 to each 8-hour shift.

In another building in Institution No. 2, 146 severely and profoundly retarded adult men lived in three bedrooms and one enormous, long dayroom with some wooden chairs. There was also a large fenced outdoor area which could be entered from the dayroom. About one-third of the residents left the building for occupational training a few hours a day. Walks outside the building and the fenced-in area were arranged three times a week. The residents were regularly served by 8 to 10 attendants during the day and by 5 during the night.

One superintendent told me about an institution in state O where a building for 180 moderately and severely mentally retarded males also had a fenced-in outdoor area. Ninety of the men were regularly led out to the fence, where they were attached with leather straps to the fence posts, their hands buckled to their waists with leather loops. They could move in a radius of only 24 inches, and along the fence there were a series of deep circles of that size.

The dayrooms at the various institutions described permitted only aimless and endless milling around or lying on the floor. No personal activity nor group interaction in any meaningful sense of the word was observed. Methods of feeding were often primitive and hurried. A superintendent told me about another institution (in state P) with 109 profoundly and severely retarded children living in four wards where one attendant has to spoon-feed 25 children in 75 minutes. Such a task can never be satisfactorily completed, as it consists of only three hurried minutes per child--the spoon clanking against the teeth.

The backwards as well as the regular wards of the large institutions I saw all had a uniform pattern: the large facilities with their often ceramic tile and terrazzo floors were seemingly constructed as extensions of the open toilet facilities. The construction seemed to make it as easy as possible for the attendants to mop up feces and urine from the floor. Organized activities, either individual or group, are out of the question in this type of setting; nor can the results of any training or occupational therapy activities be consolidated or reinforced in these dayrooms and bedroom settings. Retarded residents and attendants have little opportunity to interrelate in a personal and constructive way. In these wards, a mentally retarded person is mainly left to contacts with other retardates who might be as withdrawn, confused, and insecure as he is--the single individual always is the outsider here "where one becomes one of the far too many" (Lindegren).

But it is not only the backwards that are too large. Even the so-called good wards, houses, or sections are too large, even though they are admittedly overcrowded and understaffed. Very often the sleeping halls are designed for 30 to 40 persons, and the inhabitants of two sleeping halls frequently have to share a single common dayroom. Even in brandnew institutions I have seen sleeping facilities arranged in two sections of 28 beds with only a wall between sections. Frequently, all buildings are of the same construction, irrespective of whether they are intended for children or adults, physically disabled or ambulatory, profoundly or mildly retarded residents.

Conditions like these allow for a minimum of social life, since few meaningful contacts between individuals are feasible. There is no privacy, and nothing personal is possible. Such wards offer only dehumanizing and impersonal life conditions. The persons living in these wards seem to be anonymous, having neither name nor number. They cannot count--much less be counted upon.

Such conditions are shocking denials of human dignity. They force the retarded to function far below their levels of developmental possibilities. The large institutions where such conditions occur are no schools for proper training, nor are they hospitals for care and betterment, as they really increase mental retardation by producing further handicapping conditions for the mentally retarded. They represent a self-defeating system with shockingly dehumanizing effects. Here, hunger, for experiences is left unstilled; here, poverty in the life conditions is sustained; here, a cultural deprivation is created--with the taxpayers' money, with the concurrence of the medical profession, by the decisions of the responsible political bodies of society.

I have been told that not all the institutions are as bad as some I have seen, or that within a given institution, good buildings and programs may be found as well as bad ones. However, I find this type of apologetics difficult to understand. Even the so-called good institutions or units are too far from a decent interpretation of the rights to life, liberty, and pursuit of happiness--and in the backwards these words are almost quenchable. Prejudice is built on the seemingly firm foundation of fear--but if society's fears of the mentally retarded had any firm grounds whatsoever, the walls of the wards would have been broken through long ago. Because they understand less, have less know-how and initiative, and are essentially too kind and inoffensive, the mentally retarded have not broken through those walls, not escaped from those wards. They would have broken out and been free long ago--if they were not retarded. Who and what devised "this abyss of the rat trap and the long hour of waiting"? (Lindegren).

A reaction to conditions such as I observed cannot be sufficiently described in general terms, nor can it be made constructively meaningful without a defined point of view. The point of view which I choose to apply will be referred to as the "normalization principle," and will be discussed in a later section of this book.

Part IV: History and Development

Chapter 5

The Origin and Nature of Our Institutional Models

Wolf Wolfensberger
University of Nebraska College of Medicine

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THE ORIGIN AND NATURE OF OUR INSTITUTIONAL MODELS[1]

In this essay I will attempt to define the nature of various models which appear to underlie the design, location, and operation of residential facilities for the mentally retarded. I will then trace the historical evolution of various models that have been and are most prominent in the United States. In both tasks, I will rely heavily on original quotations, because I found that statements out of the past often have more direct impact than any attempts to rephrase or summarize them.

The Language of Architecture

There is probably little disagreement that, aside from considerations of cost or of the nature of the prospective residents, the design of residential facilities for the retarded is affected by attitudes and philosophies held by the designers and those who guide and direct them. These attitudes and philosophies may be held without the holder being conscious of their presence. Indeed, the holder may verbally and vehemently deny holding an attitude or philosophy which is strongly expressed in a building.

There are at least three dimensions of attitudes and philosophies that can be discerned in building design. These are: (1) the role expectancies the building design and atmosphere impose upon prospective residents, (2) the meaning embodied in or conveyed by a building, and (3) the focus of convenience designed into the building, i.e., whether the building was designed primarily with the convenience of the residents, the community, the staff, or the architect in mind.

Each of these three dimensions will be discussed below. However, the reader is reminded that the three dimensions are arbitrary ways of conceptualizing or analyzing the situation. Thus, there is some overlap between dimensions, and features which may be characteristic of one part of one dimension may be found to characterize parts of other dimensions. Additional dimensions can be defined with equal validity, although those defined here were felt to have particularly salient relevance to the present topic.

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[1] This essay evolved from a series of lectures and an address given before the Wisconsin Association for Retarded Children, Janesville, Wisconsin, May 1967. The writing of the paper was supported by U.S.P.H.S. Grant HD 00370 from the National Institute of Child Health and Human Development. I am indebted to my colleagues, Psychiatrist Frank Menolascino and Sociologist Richard A. Kurtz (now at Notre Dame University) for inspiration and critical reading of earlier drafts.

The term "model" will be encountered frequently in this essay. A human management model is here defined as a consistent pattern in which the behavior of persons is structured by other persons who exercise authority over them. A residential or institutional model consists of the interaction of the physical environment of the residence with the behavioral roles that managers impose upon or elicit from the managed residents.

The Perception of the Retardate's Role as a Determinant of the Institutional Models

A person's social perceptions are profoundly influenced by his basic values and orientation to life. Certain of these values and orientations have clear-cut implications to one's perception or image of the retardate and his role. And one's image of the retardate has definite implications to one's conceptualization of the residential care model appropriate for persons cast into playing the retardate role.

As Shakespeare said:

> "All the world's a stage,
> And all the men and women merely players;
> They have their exits and their entrances;
> And one man in his time plays many parts."
> (As You Like It. Act II, Scene VII, 139-142)

It is a well-established fact that a person's behavior tends to be profoundly affected by the role expectations that are placed upon him. Generally, people will play the roles they have been assigned. This permits those who define social roles to make self-fulfilling prophecies by predicting that someone cast into a certain role will emit behavior consistent with that role. Unfortunately, role-appropriate behavior will then often be interpreted to be a person's "natural" rather than elicited mode of acting.

In institutions, role performance is influenced not only by the interpersonal stimuli to which an institution resident might be exposed on the part of the institution personnel but also by the opportunities and demands of the physical environment. For instance, the environment can very clearly express the expectation that a resident is not supposed to assume any responsibility for his actions, or that he is expected to act out violently, etc. By the same token, the physical environment may impose a demand for controlled and highly socialized behavior which is clearly communicated to the prospective resident.

Social scientists in the recent past have elaborated a concept of great importance to the understanding of the behavior and management of retarded persons. The concept is that of "deviance." A person can be defined as being deviant if he is perceived as being significantly different from others in some overt aspect, and if this difference is negatively valued. An overt and negatively valued characteristic is called a "stigma."

The handicapped person is usually seen as, and expected to play the role of, a deviant. The retardate, being handicapped and often multiply stigmatized, is a deviant by definition. Too often, our texts have tried to explain attitudes toward the retarded in a narrow sense. However, to understand trends within our field, and society's response to the retarded, one must first understand societal attitudes toward deviancy generally, because a wide range of deviances may elicit similar response or expectancy patterns from people.

Wilkins (1965) suggests that our attitudes toward deviance derive from the platonic notion that goodness, truth, and beauty are related to each other, and that deviations from norms (truth) are "errors" that, by analogy, must be related to evil and ugliness. Thus, attitudes toward deviance may be rather generalized. For instance, a person may react with similar emotions toward retardation as he does toward blindness, delinquency, and senility.

It is chastening to recall that retardates in American history were long grouped with other types of deviants. In early America, the Puritans looked with suspicion on any deviation from behavioral norms, and irregular conduct was often explained in terms of the supernatural, such as witchcraft. There is reason to believe that retardates were hanged and burned on this suspicion. Later in New England, records show that lunatics, "distracted" persons, people who were non compos mentis, and those who had fits were all classed together, perhaps with vagabonds and paupers thrown in (Deutsch, 1949). Connecticut's first house of correction in 1722 was for rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers--and the mentally afflicted (Deutsch, 1949). As late as about 1820, retardates, together with other dependent deviants such as aged paupers, the sick poor, or the mentally distracted were publicly "sold" ("bid off") to the lowest bidder, i.e., bound over to the person who offered to take responsibility for them for the lowest amount of public support (Deutsch, 1949).

The 10th (1880) U.S. census first combined defectives, dependents, and delinquents for reporting purposes. The Public Health Service combined criminals, defectives, and delinquents as late as the 1920's.

The National Conference on Charities and Correction, between about 1875 and 1920, often grouped the idiotic, imbecilic and feebleminded with the deaf, dumb, blind, epileptic, insane, delinquent and offenders into one general class of "defectives." Few of us today are aware of the fact that the more contemporary term "mental defective" was coined to distinguish the retardate from these other "defectives," and it is no coincidence that many state institutions were for both the retarded and the epileptic. During the "indictment period," discussed later, an incredible range of deviances were associated with retardation; indeed, they were seen to be caused by it: illness; physical impediments; poverty; vagrancy; unemployment; alcoholism; sex offenses of various types, including prostitution and illegitimacy; crime; mental illness; and epilepsy. All these were called the "degeneracies."

"The chronic insane, the epileptic, the paralytic, the imbecile and idiot of various grades, the moral imbecile, the sexual pervert, the kleptomaniac; many, if not most, of the chronic inebriates; many of the prostitutes, tramps, and minor criminals; many habitual paupers, especially the ignorant and irresponsible mothers of illegitimate children, so common in poor houses; many of the shiftless poor, ever on the verge of pauperism and often stepping over into it; some of the blind, some deaf-mutes, some consumptives. All these classes, in varying degree with others not mentioned, are related as being effects of the one cause-which itself is the summing up of many causes-'degeneracy'" (quoted by Johnson, 1903, p. 246).

The first institutions for the retarded were built in a period of optimism regarding mental illness and the education of the deaf and blind, and many facilities for these other deviancies were erected at that time. The later disillusionment about retardation was also not isolated, but part of a more generalized aversion toward, and virtual persecution of, deviances. Farm colonies were a logical development in mental retardation, but were also part of the history of mental institutions of the same period. During the early part of the century--a very chauvinistic period--numerous writers claimed that a large proportion of retardates came from foreign-born stock, contributing to the call for more restrictive immigration laws. This is perhaps an extreme example of how retardation was linked in the minds of many to other types of deviance. One could go on endlessly demonstrating the point that societal responses toward retardation were not specific, but were part of a more generalized pattern of response toward deviance.

Historically, deviance has been handled in a number of ways.

1. Deviance can be prevented. A psycho-social means of prevention is not to attach negative value to certain types of differentness. For instance, medieval Catholicism and the more contemporary Hutterites did not place excessive value on intellectual achievement, and therefore were less likely to view the retardate as a deviant.

2. Deviance can be made undeviant, usually by means such as education, training, treatment.

3. The deviant, being perceived as unpleasant, offensive or frightening can be segregated from the mainstream of society and placed at its periphery. We have numerous examples of this in our society: we segregate the Indian in reservations, and the Negro in the ghetto; the aged are congregated in special homes, ostensibly for their own good, and these homes are often located at the periphery of our communities or in the country; deaf and blind children who could be taught in the regular schools are sent to residential schools, many of which are on the periphery of, or remote from, population centers; we have (or have had) "dying rooms" in our hospitals to save us the unpleasantness of ultimate deviancy; and the emotionally disturbed and the retarded may be placed in institutions far in the countryside.

Deviance can be seen to be someone's fault or perhaps a sign that the deviant's parents had sinned and were being punished by the Lord. The belief that blemish in the offspring is the result of punishment for parental wrongdoing appears to be deeply engrained in the unconscious of the people. Often, this belief is overtly expressed. It is a belief that had been held by Howe (a leading American pioneer in the field of retardation) and was repeatedly expressed by him. In fact, he even asserted that retardation could result from a person's own wrongdoing (Howe, 1848, 1852, 1866), e.g.: "It appeared to us certain that the existence of so many idiots in every generation must be the consequence of some violation of the natural laws;--that where there was so much suffering, there must have been sin" (1848, p. 4). Greene (1884, p. 270) said: "Our wards are innocent of crime or fault. In the large majority of instances, they are the feeble and deformed expressions of parental sins or sorrows." Parental alcoholism, for instance, was widely believed to be a major cause of retardation (e.g., Kerlin, 1886, p. 297). Perceived to be the result of sin, deviance is something to be ashamed of, hidden, and "put away." The Puritans held views along these lines (Deutsch, 1949).

4. Deviance can be destroyed. In the past, some kinds of deviance were seen to be the work of the devil or other evil forces. As such, the deviant was evil too, and had to be persecuted and destroyed so as to protect society. Destruction of deviants may also be advocated for other reasons of self-preservation or self-protection.

For instance, many societies have condoned the destruction of weaker, less adequate, or handicapped members. This was true of ancient Greece and Rome, of the Eskimos and bushmen, and of Nazi Germany. In the United States, the increasing sentiment for, and legalization of, abortion of high-risk fetuses can be viewed, at least in part, as a variant of this theme.

In one's professional functioning, in the literature, and in the history of the field, one can discern at least seven well-defined role perceptions of the retardate. Most of these roles are deviant ones. The relationship between these role perceptions, the management of the retardate, and the design of his life space, though of crucial significance, is not always obvious. I will attempt to demonstrate how location, architecture, interior appointments, and day-to-day operating procedures of institutions will tend to form interrelated patterns (management models) that are consistent with various role perceptions of the retardate.[2] Institutional models based on seven major role perceptions of the retardate will be discussed.

The Retardate as a Sick Person. One of the most prominent role perceptions of the retardate has been that of the sick person. The literature is replete with statements such as Fernald's (1915, p. 96): "The biological, economic and sociological bearings of feeble-mindedness have overshadowed the fact that it is fundamentally and essentially a medical question." A recent and unequivocal restatement of this role perception is contained in a very important document, viz., the Mental Retardation Handbook for the Primary Physician, issued by the American Medical Association (1965). In this work, mental retardation is repeatedly identified as a "disease" (e.g., p. 98) or an "illness" (e.g., p. 47).

When the retardate is viewed as a diseased organism, residential facilities are structured on the (medical) hospital model. This model tends to have the following characteristics:

1. The facility is administered by a medical hierarchy: the chief administrative officer (e.g., the superintendent) is a physician, with a hierarchy of other physicians under him, and a hierarchy of nurses under them. Concern about authority lines tends to result in a tightly controlled perpendicular administrative structure rather than a flexible subunitized one.

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[2] A similar attempt to relate psychiatric treatment approaches to schizophrenia to theoretical models can be found in Siegler and Osmond (1966). For a discussion of Osmond's collaborative efforts with architect Izumi to design buildings for residents rather than for other architects, see Bayes (1967).

2. The residence is identified or even labeled, at least in part, as a hospital (e.g., "state hospital and school").

3. Living units are referred to as nursing units or wards.

4. Residents are referred to as patients, and their retardation is identified as being a "disease" that requires a "diagnosis" and "prognosis."

5. Resident care is referred to as nursing care.

6. Case records are referred to as charts.

7. Hospital routines prevail. For example, admission procedures may require days or weeks of "observation" and residence in an "infirmary" or similar unit prior to "diagnosis" and to assignment to regular living quarters. Daily routines may resemble hospital routines in regard to rising, body inspections, sick call, charting, etc.; indeed, the daily schedule may revolve around the hinge of medication schedules. Dispension of medication, in turn, may become the model for intake of nourishment, and for other "treatments" as well. Such other treatments, even if "administered" in the form of education, may be referred to as "dosages." Usually, there is at least moderate emphasis upon convenience of "nursing care."

8. Concern with professional status symbols and status differentiation often encountered in a hospital atmosphere may be expressed by features such as presence of hierarchical staff lounges, showers, and private toilets. There may be separate vending machines for staff and "patients." Staff and residents rarely eat together. Caretaker personnel may wear uniforms. Even professional and semiprofessional personnel may wear uniforms, coats of different colors, badges, name plates with their degrees listed, and similar insignia of their role and rank.

9. Nonmedical personnel may emulate the medical role, e.g., social workers and psychologists may wear white coats or jackets, and prestigious professionals may be referred to as "doctor" even if they do not possess a doctorate degree.

10. Resident management programs are referred to as "treatments" or "therapy," e.g., recreation and work assignments may become recreational and industrial therapy. Even ordinary schooling may become educational therapy.

11. Physicians, whether qualified or not, make decisions about nonmedical matters, e.g., residents' rights and privileges, visits, work assignments, discipline, inclusion in school, training, and other programs. Even if these decisions are made by nonmedical personnel

because of temporary or permanent lack of physician manpower, this may be perceived as delegation of medical authority, and as such is perceived and interpreted as undesirable and transient.

12. Departments with the greatest affinity to medicine are given priority in program development, e.g., dentistry, orthopedics, and physical therapy may receive stronger support than behavior shaping, education, etc.

13. Physical and medical techniques are more likely to be used in managing the behavior of residents than other techniques. Thus, disturbed residents are more likely to be physically restricted or settled with drugs than to be counseled or trained; residents with seizures may be placed on anticonvulsant medication with little thought given to environmental manipulation of seizure-precipitating events or to educating the person to develop preventive behavior habits.

14. There exists an excessive abhorrence of any chance or likelihood of injury to the retardate. On the one hand, this is exemplified by lack of stairs and steps, sharp objects and corners, conventional electrical outlets, and access to conventional hot water faucets; etc. On the other hand, it is exemplified by the presence of special features such as ramps, screening of radiators, and screened stairways (if any).

15. A disease conceptualization of retardation tends to result in a management dilemma. On the one hand, such a conceptualization often results in pursuit of treatment hoped to result in cure; on the other hand, unless a "cure" is seen as likely, the management atmosphere is often permeated with hopelessness and treatment nihilism. In other words, the disease conceptualization tends to be correlated with inappropriate extremes of management attitudes.

The Retardate as a Subhuman Organism. The fact that deviant subgroups within a culture may be perceived as not fully human has long been recognized. To this day, large segments of our population deny full humanity to members of certain minority groups such as Negroes and American Indians. Retardates are particularly apt to be unconsciously perceived or even consciously labeled as subhuman, as animal-like, or even as "vegetables" or "vegetative."

The literature of the field is richly endowed with labels alluding to the alleged subhuman nature of the retarded. The term "garden variety," widely used by professionals in the field to refer to cultural-familial retardates, has definite vegetative connotations. It is interesting to note that the vegetable concept may, in part, have been derived from an inappropriate transfer of the medical concept of "vegetative functions." In medicine, the "vital functions" controlled by the autonomic nervous system and/or the hypothalamus may be referred to as "vegetative." These functions, which include temperature, heart rate, blood pressure, respiration rate, etc., are possessed by all humans and most animal species, and yet the concept of vegetative functions appears to have been translated into the social context in such a way as to abrogate even the animal, not to mention human, qualities of a person.

Luther, in describing what appears to have been a severely or profoundly retarded child, denied the child's humanity as follows: "Eight years ago, there was one at Dessau whom I, Martinus Luther, saw and grappled with. He was twelve years old, had the use of his eyes and all his senses, so that one might think that he was a normal child. But he did nothing but gorge himself as much as four peasants or threshers. He ate, defecated and drooled and, if anyone tackled him, he screamed. If things didn't go well, he wept. So I said to the Prince of Anhalt: 'If I were the Prince, I should take this child to the Moldau River which flows near Dessau and drown him.' But the Prince of Anhalt and the Prince of Saxony, who happened to be present, refused to follow my advice. Thereupon I said: 'Well, then the Christians shall order the Lord's Prayer to be said in church and pray that the dear Lord take the Devil away.' This was done daily in Dessau and the changeling died in the following year. When Luther was asked why he had made such a recommendation, he replied that he was firmly of the opinion that such changelings were merely a mass of flesh, a _massa carnis_, with no soul. For it is the Devil's power that he corrupts people who have reason and souls when he possesses them. The Devil sits in such changelings where their soul should have been!"[3]

Deutsch (1949) pointed out that by some peculiar twist of logic, the mentally ill were often apt to be stripped of their human attributes, together with their rights and privileges as human beings. Obviously, it is even easier to dehumanize a person who never possessed much reason if one dehumanizes him who had reason but lost it. The idea that the mentally afflicted lack sensory acuity, e.g., that they are insensitive to heat and cold, was popular into the mid 1800's (Deutsch, 1949). This myth resulted in their often being denied heat during the winter in the cold cells of institutions, and may well have contributed to the image of the retardate as an insensate vegetable. To this day, retardates, like army recruits, may be said to need "being broken" or tamed, like horses or wild beasts. Just recently (_Atlantic Monthly_, October 1967, p. 49) a reader called for the

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[3] There are several versions of this account, derived from the various editions of Luther's Tabletalks, e.g., _Luther's Works_, Vol. 54, Fortress Press, Philadelphia, 1967, p. 396, and Aurifaber, Jr., _Tischreden_, Vol. 5, Weimar Edition, p. 9. In all editions the account is item No. 5207.

"... sacrifice of mentally defective humans, or human vegetables..."to provide organ transplants and"...increase the intellectual betterment of mankind..." Dehumanization of the retardate is so accepted, even to this day, and even by workers in our own field, that we witness a public statement by a contemporary superintendent of a state institution referring to retardates as "...so-called human beings..." "below what we might call an animal level of functioning..." (Frontiers of Hospital Psychiatry, 1968, 5, 5-6).

The atmosphere and design of a residential facility can very clearly express an expectancy that the resident will behave in a subhuman fashion--no matter how vociferously the staff may deny adherence to dehumanizing attitudes. Such expectancies are implicit in any of virtually hundreds of dehumanizing practices encountered in institutions and enumerated by Vail (1966). Some of the more common expectancies will be listed and briefly elucidated here.

1. The perception of the retardate as an animal usually implies an expectation that he behave in a primitive, uncontrolled fashion. Thus, the environment is designed to be "abuse-resistant," which implies measures such as:

(a) Walls, floors, etc., made of material that is indestructible.

(b) Unbreakable, shatterproof or wire-enmeshed glass in windows and partitions.

(c) Installation of the sturdiest, most heavy-duty furniture and equipment.

(d) Minimization of moving parts.

(e) High ceilings with recessed or specially shielded or laminated light fixtures, to minimize damage due to throwing of objects.

(f) Soundproofing to muffle the sounds residents are expected to emit; such sound proofing may even be installed in areas designed for retardates quite capable of learning adaptive behavior.

(g) Television sets protected with wire screens, recessed into protective housing, and/or placed above reach.

2. A presumably subhuman retardate is usually perceived as being potentially assaultive, destructive, and lacking in self-direction and constructive purpose; this necessitates restricting his movements both to control him more easily and to protect either the

human from the subhuman or one subhuman from another. This characteristically leads to a number of measures:

(a) Locked living units.

(b) Locked areas within living units. In the case of children or the physically handicapped, door knobs may be set high and above reach, or complicated release mechanisms may be installed. This permits staff to perceive the facility as "open" even though it is *de facto* locked.

(c) Doors made from heavy material; bedroom doors can be locked only from the outside, and often open outward rather than inward, as in most homes or offices.

(d) Barred windows. More sophisticated but equally effective are the reinforced window screens, or so-called security screening.

(e) Outdoor play areas enclosed by either high walls or high, strong fences or by both. Often, these areas are quite small (and therefore easier to control), and not sufficiently large, or equipped, for adequate exercise. Such small areas again permit the staff to engage in conscience-salving self-deception. I once inquired of a nurse whether the children in her locked living unit were ever dressed up and taken outdoors. She assured me that the children were dressed and taken for outdoor walks every day. The woman was not hypocritical; she was only rephrasing reality so that she could live with it. The reality was that these moderately to severely retarded ambulatory children did not leave the building confines for months, perhaps years, at a time. "Dressing" meant to put on more clothes than underpants and diapers; and "going for a walk outdoors" meant being turned loose in large groups with minimal supervision in a small outdoor enclave enclosed by high brick walls on two sides and high wire fences on the other two sides.

(f) A fence or wall surrounding entire buildings or even an entire facility complex.

(g) Segregation of sexes. Such segregation may assume absurd proportions when practiced with infants and children, or with the aged retarded.

A typical programmatic, rather than architectural, expression of the subhuman view surrounds the "feeding" of retardates. To this day, food and drink may be served in unbreakable tin reminiscent of prison riot films of the 1930's. Often no knives and forks are permitted. The latter measure also necessitates the serving of special foods, such as finger foods or soft homogenized pap that can be spooned.

3. Since the perceived subhuman is not believed to be capable of meaningful controlled choice behavior, he is permitted minimal control over his environment. This typically implies the following:

(a) Switches controlling the lights in resident areas such dayrooms, sleeping quarters, toilets, etc., are made inaccessible to residents by placement in staff control areas such as nursing stations, placement in locked cabinets, or keying (i.e., a key is required to turn a light on or off).

(b) Water temperature in lavatories, showers, etc., is controlled by thermostats. The water flow itself may be controlled by caretakers by means of removable and portable handles.

(c) Temperature, humidity, and air movement controls are locked or keyed.

(d) Radiators are locked, recessed, or screened.

(e) Residents are usually forbidden to carry matches or lighters.

4. Perception of the retardate as an animal implies an emphasis on efficient "keeping" of residents, rather than on interaction with caretaker personnel. Consequently, the environment is designed for efficient supervision.

(a) Caretakers work behind isolating (protective?) partitions which keep out residents and perhaps even their sounds but permit extensive or complete visual monitoring. A stated rationale here may be that isolation makes for greater efficiency in certain caretaker tasks such as visual supervision, record keeping, administration of medications.

(b) Residents sleep in large dormitories, with no or only low partitions between beds. Lights may burn even at night to facilitate supervision.

(c) Caretakers engage excessively in tasks minimizing chances for interaction. For example, supervisory staff may be isolated in a separate building. Living units may be widely dispersed and removed so that ready interaction between staff and residents is difficult to achieve; in one such widely dispersed residential complex I have known, low staff interaction with residents was partially due to the fact that walking was both time-consuming and often not feasible due to bad weather, and driving was inconvenient because of lack of parking space near the residential units. Even staff meetings and in-service training activities can become an unconscious legitimization of noninteraction with residents.

(d) There is much emphasis on use of drugs (chemical straight jackets?), rather than human interaction, to control and shape behavior.

(e) The placement of residential centers far from population centers and towns can, in some cases, be a correlate of a "keeping" or "controlling" desire.

5. Subhumans are perceived to "live like animals," i.e., to soil themselves and their habitat. This results in design of an environment that can be cleaned easily, frequently, efficiently, and on a massive scale:

(a) Walls and floors may be made of a material that is virtually impossible to "deface," i.e., scratch, soil, stain, etc., and that can be hosed down (like in a zoo); there may be drains in the floors of living areas.

(b) Beds or bed stalls may be designed to be picked up and immersed in cleansing solutions in their entirety by means of cranes.

(c) Resident bathing facilities may be designed for efficient cleansing of large numbers of residents by small numbers of caretakers; there may be slabs, hoses, and mass showers, rather than installations conducive to self-conducted cleansing or the learning thereof.

6. Typically, subhuman retardates are either not expected to learn or develop appreciably, or the growth potential of retardates is seen as so small as to be irrelevant, since it will never lead to complete "humanization." In other words, the state of subhumanity is

perceived as being essentially permanent. In consequence, the environment is designed to maintain a resident's level of functioning but not to provide opportunities for further growth and development.

7. Animals have no rights; it follows that retardates perceived to lack humanity are also perceived to lack certain rights. Among these are:

(a) The right to privacy. Toilets and showers for the retarded may lack partitions, curtains, or doors. Bedrooms often lack doors, not to mention that the bedrooms themselves may be lacking. Where doors exist, they almost always have window panes or so-called "Judas-windows" (complete with wire-enmeshed glass or peepholes). Private visiting space may be nonexisting.

(b) The right to property. Institutionalized retardates may have few or no possessions. Often they have no space to store possessions, or lack ready access to such space or control over it. Residents are usually denied the privilege of locking up their possessions, carrying the key, and using it without restrictions. Children typically do not have use of personalized clothing, and children of the same size (sometimes of various sizes, may share the same pool of clothes. All of these points have implications as to architectural design, especially regarding space allocations and selection of built-in furniture. Residents may be seen as not entitled to pay for their work, or to carry actual currency even if they do own money. "Poverty in a mental hospital is no less dehumanizing than in a slum. . . " (Bartlett, 1967, p. 92).

(c) The right to communicate freely. There may be censorship of incoming and outgoing mail, although some forms of censorship may not be perceived as constituting censorship. Telephone usage may be severely restricted. Visiting is usually restricted for several weeks after admission.

(d) The right to individuality. As described so well by Vail (1966), residents are regimented and managed in groups, even where individual management might be feasible. For example, residents are mass-showered where education for individual showering is possible; residents may even be mass-toileted, which accounts for the fact that some living units have more toilet seats than would be needed for, say, an equivalent-sized college dormitory.

8. The assumption that the retardate lacks esthetic sense is a subtle but important corrolary of the subhuman view. This corrolary results in the creation of unattractive residential living environments, since funds spent on beauty are seen as wasted on retardates. The drab, monotonous design and furnishing of retardates' residences (sometimes in contrast to staff living quarters) is usually a testimony to this view. Rarely does one see furniture that is both comfortable and attractive in lines and color in institutions for the retarded, and even yet more rarely is there furniture-zoning so that the furniture reflects the mood and function of different living areas in an attractive fashion.

The degree to which retardates can appreciate beauty is really only one of two important issues involved here. The second important issue is that observers' (e.g., the public's or employees') attitudes are shaped by the context in which retardates are presented to them. Even if intellectual limitation does impair retardates' esthetic sense, to deprive their environment of beauty is likely to predispose an observer to view them as subhuman.

Caretakers sometimes claim that drabness is due to lack of funds, but this is often untrue because much beauty can be provided at little or no cost. In my own institutional work, I recall trying to mount attractive pictures on walls of several children's living units that had a severely deprived atmosphere. There was no support for this project from the institutional power echelons; nursing and housekeeping services objected to the "defacing" of the walls; and the pictures which actually got put up were pulled down (by personnel) within days.

A 1964 prospectus, written by the staff of an institution, contained the following instructions to an architect regarding the design of a new residence building for adult and young adult "trainable" retardates: "All interior wall surfaces shall be of a smooth material, and without wall projections other than those specifically stated. All thermostats should be protected with a guard to avoid tampering. Window areas shall be kept consistent with patient needs. Excessive window areas are not desirable. Consideration should be given to using shatterproof glass in patient areas. Door louvers in patient areas should be made of a steel material to withstand patient abuse. Mechanical and electrical equipment and controls throughout the building shall either be tamperproof or located outside the patient areas. Maximum water temperatures for bath and lavatories must be automatically controlled to eliminate the possibility of scalding. Switches in large patient areas shall be located on the outside of the rooms. A cubicle measuring 24" x 12" x 12" should be provided for each patient." While such instructions are not conclusive evidence that the instructors held a "subhuman" view of retardates, such instructions certainly appear to be consistent with such a view.

It cannot be emphasized too strongly that the alleviation of dehumanizing and other undesirable management practices is ultimately more a matter of attitude, rather than of money as widely claimed. There have always been residential facilities that provided exemplary service at very low cost. Usually, such facilities were small, privately operated, and affiliated with religious organizations. On the other hand, one can point to public institutions in this country where even generous funding and high staff-to-resident ratios have failed to change old practices. Eight attendants can look at 75 residents from behind an unbreakable glass shield as easily as one attendant can, and I have known an institution where this was the sanctioned pattern.

The Retardate as a Menace. Unknown events or objects, if alien enough, tend to arouse negative feelings in both man and beast. Man's history consists mostly of his persecution of fellow men who were different in features, skin pigmentation, size, shape, language, customs, dress, etc., and it is apparent that man has been apt to see evil in deviance. It is not surprising that one role perception prominent in the history of the field is that of the retardate as a menace. The retardate might be perceived as being a menace individually because of alleged propensities toward various crimes against persons and property; or he might be perceived as a social menace because of alleged contribution to social disorganization and genetic decline.

The residential care model derived from the menace perception has much in common with the subhuman model. Certain features, such as segregation from the community, as well as segregation of the sexes, are likely to be accentuated. Since the menace model may ascribe a certain willfulness and evil intent to the retardate (in marked contrast to the medical model), an element of vindictiveness and persecution may enter into his management, and some of the protective features of the subhuman model may be omitted. Otherwise, residential features of both models have much in common.

The history of the menace model in the United States will be reviewed later in this essay.

The Retardate as an Object of Pity. One residential model is based upon the image of the retardate as an object of pity. Persons possessed of such an image will often hold one or more correlated views:

1. The retardate is seen as "suffering" from his condition, and there is emphasis on alleviation of this suffering.

2. Although the retardate may be seen as "suffering," he may also be believed to be unaware of his deviance.

3. The retardate is seen as "an eternal child" who "never grows."

4. Being held blameless for his condition, the retardate is seen as not accountable for his behavior.

5. The retardate is viewed with a "there but for the grace of God go I" attitude.

In residential care, the "pity image" will tend to be expressed in a paternalistic environment (1) which shelters the resident against injury and risk and (2) which will make few demands for growth, development, and personal responsibility. Both these features may imply infantilization and lack of risks and environmental demands such as stairs, sharp edges, hot water, hot heaters, and electric outlets, as discussed previously.

The pity model has some features in common with the disease and subhuman models. However, there are important differentiating features. The pity model strives to bestow "happiness" upon the retardate, usually by means of emphasis on programs of fun, religious nurture, and activity for its own sake. This, in turn, is likely to result in allocation of generous space and facilities for music, arts, crafts, parties, picnics, and worship (e.g., a chapel on the grounds).

It is no coincidence that the pity model shares features with the subhuman model: it has many similarities to Vail's (1966) definition of the "man-as-trivium" (i.e., a human being who is not taken seriously or given importance) mode of dehumanization.

The Retardate as a Burden of Charity. A person with a strongly moralistic conscience but with little genuine humanism is apt to perceive the retardate as an object of a sour charity. This attitude can best be stereotyped as being that of the Victorian age toward orphans. In colonial America, handicaps were looked upon as the consequence of a stern providence meting out judgment for wickedness. Thus, a natural response to deformity and misfortune might be contempt more than sympathy, and whatever help was rendered was "cold charity" (Deutsch, 1949). The historical roots of state institutions were consistent with this view, since these institutions evolved, in part, from charitable homes for "paupers," orphans, vagrants, etc., (Bartlett, 1967). Even the first institutions for the retarded emphasized admission of children whose parents were unable to provide for their support (see Journal of Insanity, 1852, p. 29).

The sour humanist may look upon a retarded resident as a kept object of (public) charity. Charity clients are seen as entitled to food and shelter, but not to anything interpretable as luxuries, frills, and extras. A residence based on this model will be austere and lacking in privacy, individuality, and opportunities to have personal possessions. The resident is expected to be grateful, and to work as much as possible for his "keep." An example of a Victorian "burden of charity" view is found in the following quotation taken from the Massachusetts report at the 1890 National Conference on Charities and Correction: "As to the State schools, it recognizes the value only of such teaching, mental or manual, as shall develop the boy or girl and tend toward a honest and respectable life outside the institution." "It disapproves of extravagant or luxurious appointments in institutions, as foreign to the spirit of true charity. The inevitable weakening of character by life in institutions, the arrest of development, must be prevented, if possible, by some hardships and privations, such as these boys and girls would be sure to encounter in their own homes or those to which they would be sent" (Reports from States, 1890, p. 329).

Again, much of the physical environment implied by this model will be similar to that of the subhuman model; however, there are certain differentiating architectural and program implications. In a residence built on the charity model, there will be little emphasis upon segregation of retardates from the rest of society. There will be a grim and unimaginative emphasis upon eventual self-sufficiency, and while there will be little stress upon environmental enrichment as a means of fostering development, education and training in the traditional handcrafts are likely to be strongly valued.

The Retardate as a Holy Innocent. Retardates, and possibly persons with other handicaps as well, have occasionally been perceived as the special children of God. As such, they are usually seen as incapable of committing evil voluntarily, and consequently may be considered to be living saints. It may also be believed that they have been sent by God for some special purpose.

The role of the retardate as a holy or eternal innocent has been recognized in a number of cultures and eras. This role perception was reportedly prevalent among the American Indians, and in medieval Europe. The concept of "L'enfant du Bon Dieu" embodies this image.

The holy innocent role has probably had a stronger influence on residential care thinking than is realized--albeit in a subtle way. The holy innocent was generally considered to be harmless, or was indulged much like a child. His presence may even have been valued, as it made the beholder feel a bit closer to heaven and to God. Thus, this role perception tended to inhibit the development of specially designated residential facilities, as the innocent were gladly accepted and integrated into the family and the heart of the community. A contemporary example is the Hutterite communities in the United States, studied by Eaton and Weil (1955). In these communities, not one retardate had been institutionalized; instead retardates were accepted and integrated into the community life.

While the holy innocent perception inhibited the development of special residential placement, it did not prevent it altogether. If residential placement was achieved, however, it tended to be of a very special kind. It might involve placement of the retarded in a child-like role in a godly home; as menial workers in religious communities such as monasteries; or as workers in nursing homes or hospitals run by religious orders. One variant of this practice exists in the Belgian town of Geel, where, for centuries, thousands of the mentally handicapped have been boarded in an atmosphere of sheltered benevolence in ordinary homes and have the liberty of the city. The presence of a religious shrine to St. Dymphna--long believed to be the patron saint of the mentally afflicted--gave rise to this practice.

Despite its good intentions, the holy innocent model has common elements with a dehumanizing ("man as other") perception described by Vail (1966).

The Retardate as a Developing Person. The developmental model takes an optimistic view of the modifiability of behavior, and usually it does not invest the differentness of the retardate with strong negative value. Retardates, even if severely retarded, are perceived as capable of growth, development, and learning. The developmental model is characterized by architecture designed to (1) facilitate and encourage the resident's interaction with the environment; (2) maximize interaction between staff and residents; (3) foster individuality, dignity, privacy, and personal responsibility; (4) furnish residents with living conditions which not only permit but encourage functioning similar to that of nonhandicapped community age peers.

In other words, the developmental model provides an atmosphere as similar as possible to that of a typical home, while introducing some additional features which either compensate for handicaps, and/or maximize the likelihood of developmental growth. Administratively, the developmental model will naturally tend to be a decentralized one, in contrast to the medical model, as a resident-oriented atmosphere demands that staff in immediate contact with residents must possess flexibility and freedom to make rapid decisions.

Specific features of the developmental model might include:

(1) Homelike internal and external design.

(2) Colorful, light, bright, perceptually warm but diversified living units.

(3) Small, self-contained living units.

(4) Bedrooms for 1-4 residents.

(5) Family dining facilities.

(6) Homelike appliances such as toilets, faucets, showers, baths, stoves.

(7) Nonstandardization of design and furnishings of living units within a larger residential complex.

(8) Windows of normal size, type, and placement.

(9) Live-in care personnel.

(10) Plenty of space for individual possessions.

(11) Doors between rooms and areas.

(12) Curtains or doors for baths and showers, and toilets designed for private use.

(13) Homelike access to "controls" such as switches and thermostats. (The idea here, as with other features, is that potentially objectionable behavior will be modified by interaction with caretakers, rather than being made impossible by the design of the physical environments.

(14) Access to "risks," e.g., stairs, electrical outlets, hot water, etc. (Again, the assumption is that residents will be trained to act adaptively, and that controlled risk is part of normal life.)

The developmental model implies less of a perception of the retardate as a deviant, while striving optimistically to minimize, or compensate for, what deviance there may be. In terms of the old cliche, the retarded are seen as more like, than unlike, others. Although particularly appropriate for children, the developmental model is equally meaningful when applied to adults.

O. R. Lindsley once said that our society is willing to spend money on the design of environments that maintain life, but not on those that maintain dignified behavior. Of all management models, the developmental one is probably most likely to provide the framework for a cathedral of human dignity.

Other Roles of the Retardate. In addition to the six roles discussed above, there are other rather well-defined roles into which retardates have frequently been cast. For instance, there is the role of the retardate as an object of merriment and ridicule, exemplified in an extreme form in the functioning of retardates as court fools and jesters. Though historically prominent, these roles will not be examined further because they have had little effect upon residential care models.

The Meaning of a Building

That buildings have symbolic qualities is probably universally recognized. This symbolic quality is the meaning referred to here.

Samuel Gridley Howe was probably the most significant and foresighted figure in American history of special education. Through my perusal of original documents, I have formed the conclusion that his role has not yet been fully appreciated, especially vis-a-vis more flamboyant personalities such as Seguin. In 1866, Howe gave the dedication address at the cornerstone-laying of a new institution for the blind in Batavia, New York. By that time, he had been instrumental in founding the early U.S. institutions for both the blind and retarded, had been superintendent of the first such public institution for the retarded (in Massachusetts), and had already perceived and accurately defined most of the shortcomings under which institutions were to labor for the next 100 years. To capture fully the eloquence of Howe's statement on the language of architecture, I have excerpted several passages from his 1866 (pp. 13-16) dedication address:

"Language is of vast extent, and speech is only one of its powers. By speech and by print, men of our generation hold intercourse with each other. There are, moreover, some sorts of language by which the generations of men hold intercourse with other generations, and by which they converse across centuries and cycles of time. Among the various forms of language between generations, and between the ages, monuments hold a high place.

"As men and women unwittingly, and sometimes unwillingly, reveal their character, and even their secret motives of action, by the sort of language which they use, so the generations unwittingly reveal the prevailing ideas of the men who lived in them, by the works which they leave behind them. Consider the Pyramids of Egypt, and read the speech which they utter ... What say the ten million cubic feet of solid masonry, enclosing two or three small chambers, whose entrances are so narrow that the enclosed sarcophagus must have been placed therein before the walls were built; and those entrances afterwards closed up by huge blocks of stone, too heavy to be moved by any common force? What does all this tell?--What is the language of that generation, spoken by the tongues of the pyramids to this generation?

"It is, that the monarchs were absolute, selfish, cruel and short-sighted. That they built these vast monuments to preserve their fame from oblivion, and their bodies from disturbance ... The monuments tell us, moreover, that the people must have been ignorant, oppressed, and like 'dumb, driven cattle.'

"They tell us, that great multitudes of men and women were driven in from towns and villages, to toil and moil, and lift stones and carry sand for weeks and months; and when some had died and all were exhausted, then that fresh gangs were driven in to take their places.

"And so of smaller monuments, whether the triumphal arch, where the chained captive walks sadly behind the sculptured conquerors; or the storied column, with its winding procession of battles, assaults and sieges, leading up to the proud victor standing self-glorified on the top. And so of those which tell a better story -- the aqueducts, the fountains, the bridges, the canals, the docks and the like.

"If we study the monuments which a generation built, and the kind of men in whose honor they raised statues, we may learn much of the character of the people themselves.

"You are assembled to lay the foundations of a monument which will speak to future generations; and although what you grave upon the cornerstone, and what you put within it, should never be seen, the monument itself will talk to future generations; and what will it tell them?

"It will disclose that the physical condition of the human race in this country was imperfect and unfavorable and that there were born to this generation, and expected to be born in the next , . . . children, numerous enough to form a persistent class. That children of this class were not only loved and cherished by their parents and kindred, but also cared for by the public. That there was no Mount Taygetus here, on which to expose them, with other infirm folk, to perish or be devoured, but asylums into which they were gathered and nurtured.

"It will prove that the social and political union which here leagued three million people into one powerful State, was formed and maintained not only for defence against enemies, for common commercial interest, for great enterprises, for social prosperity and enjoyment, nor yet for mental culture and high civilization of the many, but also for the protection and care of the weak and infirm. That the State of New York, which could dig out a navigable river clear across her broad land, -- which had just armed and sent forth three hundred thousand sturdy soldiers to serve the common country and the cause of humanity, -- that this great State, while holding on in her high career of material prosperity, and providing schools for all the children, took thought also, that not even the . . . little ones should be neglected.

"In such language will the building, those foundation-stone you this day lay, speak to many generations in coming time.

"But, while thus noting with pleasure and even excusable pride, the humane impulses which prompt and which will carry forward the work, pardon me if I utter a word of warning.

"Good intentions, and kind impulses, do not necessarily lead to wise and truly humane measure.

"Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other and equally important half."

A later superintendent from Massachusetts offered an equally relevant insight:

"The history of the development of the human race has been most enduringly written in its architecture. A study of the architecture of a people reveals their dominant thoughts and ideals. The caves of the cave-dweller suggest man's early struggle for existence against wild beasts; the tents of the ancient shepherds the nomadic traits of these people in their moving from place to place in search of food for their flocks. The religious fervor of the middle ages is unmistakably recorded in the cathedral monuments of Europe. The creative and commercial ideals of nations are accurately recorded in their factories, warehouses, docks, highways, and office buildings, and their warlike instincts are well gauged by their forts, armories, battleships, tanks and aeroplanes; their educational interests by their schools and higher seats of learning; their interest in the sick and handicapped are clearly recorded in their hospitals and eleemosynary institutions" (Wallace, 1924, p. 256).

Buildings for the retarded, like other buildings, can project many meanings. Certain of these meanings are of particular relevance to our discussion. I propose that at least three such relevant meanings can be readily recognized in retardation facilities: The building as a monument, as a public relations medium, and as a medium of service. Each will be discussed briefly.

The Building as a Monument. Buildings are often erected, consciously or unconsciously, as monuments. In mental retardation facilities, this is especially likely to be true of administration and medical treatment units. The monument may be to a governor; a famous man; a foundation donor, or donor dynasty; or an administrator or professional who may want to achieve identity or "immortality" through this monument-building. Common examples of the latter are the aged superintendent or administrator who wants to make one last, only, or major, contribution before he retires or dies.

While such aspirations often result in genuine benefits to mankind, they can also pervert the consciously verbalized or officially defined purpose of the building. For example, in order to fulfill its function as a monument, the building may be erected in a locality not consistent with optimal program development; available funds may have been so plentiful as to result in a building that is either larger than optimal or overequipped; limitations of funds may result in a building so small as to require wasteful duplications and adjustment later; the ambitions of the initiator may require a free-standing building where an additional wing or floor on existing buildings would have been preferable; or the concepts which the initiator imposes upon the building plans may force future human services into undesirable and hard-to-remedy patterns. Examples of the latter are donations of facilities such as swimming halls, medical buildings, or churches. The existence of such facilities often makes it very difficult later to establish a pattern of increased use of the community for recreation, medical services, and church attendance. Similarly, an expensive new service building designed to serve large numbers of residents can become a great obstacle to reduction of an institution to a smaller size.

"Let us remember that our purpose is not to build costly monuments, at the expense of the taxpayer, to architects, legislators and governors or indeed to ourselves, . . . " (Kirkbride, 1916, p. 256).

The Building as a Public Relations Medium. A building, or an entire facility, can become a medium of public relations. While such a medium may produce desirable and beneficial results in the long run, the public relations functions may also be irrelevant and even detrimental to the welfare of current residents. A number of examples follow.

1. The building may function as an advertisement for the architect. There are many instances of widely acclaimed buildings which had serious functional shortcomings.

2. Innovations in design may become means of aggrandizement or advancement to staff or superintendents. Real benefits of novel designs may be blown up beyond all proportion. Other widely hailed

design innovations may later be recognized as gigantic and foreseeable errors. For example, one institution in the late 1950's erected a new showcase nursery in which the infants' cribs had solid (and expensive) marble sides and wire mesh fronts. Among other things, this obviously could lead to injuries, especially to children with seizures. Only a few years later, the cribs had to be rebuilt at great expense. This was hailed as another dynamic innovation rather than as rectification of a predictable blunder.

3. Finally, a building may be a public relations tool for a governmental or political body. The building may be designed to win votes or good will, to gain power by providing employment opportunities and/or patronage, etc. Again, such buildings may do more harm than good. Erection of large institutions in isolated areas has often been prompted by such public relations, rather than service, considerations.

The Building as a Medium of Service. Finally, buildings may be designed truly and completely with service and function considerations in mind. In residential centers in the United States, such buildings are more likely to be encountered in private rather than public agencies. Too many of our public residential buildings and facilities reflect political, economic, and other considerations which have little to do with resident welfare.

The Focus of Convenience of a Building

Social norms demand that when a residence of some sort is constructed, we must pretend and proclaim that the building is designed for the convenience of the prospective residents. In reality, the building may be designed to serve the convenience of the builder (architect?). If residences are erected with public funds, the convenience of the community can easily become a primary consideration. If the prospective residents belong to a deviant subgroup that requires special management, then the building may be designed for the convenience of the "manager" (who is usually not a resident) rather than the "managed" resident.

The Convenience of the Architect. Some buildings are designed for the convenience of the architectural agent. Such buildings may have required the least imagination, planning, and work from the architect or engineer, while perhaps resulting in the largest profit to him. Many ill-designed, ill-constructed buildings and building complexes bespeak an utter disregard for the prospective resident. However, the building as a monument to the architect, though perhaps well-designed for external beauty and effect, may also fall into the "convenience of the architect" category if resident welfare is neglected.

The Convenience of the Community. The location of a large proportion of institutions in the United States was determined by economic considerations. Institutions were often placed in areas where jobs were needed, and placement became a very political matter. In many instances, institutions were located by the accident of land donations by job-hungry communities. Locations of this nature were not only ill-advised as far as the retardate was concerned, but also inconvenient to retardates' families. Furthermore, they resulted in professional and scientific isolation of the staff.

To locate any human service agency with the needs of the server rather than the served in mind is analogous to requiring people to eat in order to provide employment to cooks.

The Convenience of the Staff. Many buildings, when entered, leave little doubt that staff convenience was paramount in the designer's mind. Characteristic elements may include the following:

(1) Caretaker stations providing maximal visual control over resident areas, while minimizing staff involvement; the glass-enclosed nursing station is a classical example.

(2) "Segregated" staff lounges to which caretakers withdraw for meals, coffee, rest, etc.

(3) Air conditioning for staff, but not for resident areas.

(4) Services such as classrooms, beauty shops, barber shops, and therapy areas that are located in the living units, saving staff the effort of dressing residents or escorting them to other buildings.

The Convenience of the Resident. If built for the welfare and convenience of residents, the location, size, type, and internal arrangement of most buildings and institutions in the United States would have been radically different from what they typically have been and are. Again, private facilities appear to have been more apt to be structured with the convenience of residents in mind.

The Evolution of Institutional Models in the United States

Having discussed certain architectural considerations, and having defined a number of models implicit in various management approaches to retardates in general and to their residential management specifically, I will now try to trace the residential service models that have been most prominently with us today.

There is a riddle that holds a moral: if fish were intelligent creatures and had scientists and thinkers among them, what would be one of the last things they would probably discover? The answer to the riddle is supposed to be "water." After all, man discovered air only about 300 years ago.

Why do we have institutions at all? Why were they built, and why are they the way they are, and not some other way? Like fish, we have grown up with the fact that institutions exist and that they are places where retarded people are sent. Taking institutions for granted, we have perhaps failed to consider that there are societies that do not have them, or have them in quite a different form than we know.

The last major attempt to interpret rather than merely recount the history of institutions for the retarded in the United States appears to have been made by Davies (1930).[4] His interpretations have been accepted essentially intact by subsequent workers and writers in the field. However, we must consider that as elegant as his interpretations were, they were very close to many historical events he tried to interpret. With another 40 years of perspective behind us, it now seems appropriate to take a fresh look at history, and I will propose some new interpretations or elaborations in an attempt to gain further insight into the nature and origins of our institutional models. Particularly, I will try to demonstrate that attitudes toward deviance generally have had much to do with the original rise of institutions for the retarded in the United States, and with the way the more common residential models were shaped.

Making the Deviant Undeviant

Around 1850, institutions for a number of deviant groups in the United States were founded for the purpose of making the deviant less deviant. The main means whereby this was to be accomplished was education. In effect, the argument was that deviants had to be congregated in one place so that expert and intensive attention could be concentrated on them. I must take issue with the now prevailing notion that the aim of the founding figures in our field was to erase retardation in a child. From reading primary sources, I conclude that the goal was a combination of diminishing the intellectual impairment and increasing adaptive and compensatory skills of the pupil so that he would be able to function at least minimally in society.

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[4] Sloan (1963) brilliantly related the relevance of social movements to the history of mental retardation. However, his essay was not specifically concerned with institutions.

Wilbur (as quoted in Journal of Insanity, 1852, p. 31 ff.) stated:

> "We do not propose to create or supply faculties absolutely wanting; nor to bring all grades of idiocy to the same standard of development or discipline; nor to make them all capable of sustaining, creditably, all the relations of a social and moral life; but rather to give to dormant faculties the greatest practicable development, and to apply those awakened faculties to a useful purpose under the control of an aroused and disciplined will.
>
> "But great as are the benefits of education in ordinary cases, its achievements are still greater when, instead of increasing the capacities of the pupils, it substitutes capacities for incapacities; when it restores a class of human beings, now a burden to community, destitute of intelligence, degraded and miserable, to their friends and to society, more capable of development, under the ordinary circumstances of human development; nearer the common standard of humanity, in all respects; more capable of understanding and obeying human laws; of perceiving and yielding to moral obligations; more capable of self-assistance, of self-support, of self-respect, and of obtaining the greatest degree of comfort and happiness with their small means."

The institution was seen as a temporary boarding school. After the child was improved so as to have mastered skills necessary in society, he was to be returned to his family and/or the regular schools. It certainly was not the intent of the pioneers that the institution should become a permanent home. For example, Samuel Gridley Howe said in 1851 of what is now Fernald State School: "This establishment, being intended for a school, should not be converted into an establishment for incurables" (Journal of Insanity, 1852, p. 270). "The early teachers of the feeble-minded jealously guarded their schools from the danger of becoming asylums. Admission was restricted to those classed as improvables..." (Johnson, 1898, p. 465). The institution was seen as ". . . a link in the chain of common schools--the last indeed, but still one necessary in order to make the chain embrace all the children in the state" (Howe, 1852, pp. 15-16). The 1851 bylaws of the first mental retardation institution in New York, opened by Wilbur, are reported to have stated:

> "The design and object of the asylum . . . are not of a custodial character but are to furnish all the means of education to that portion of the youth of the state not provided for in any of its other educational institutions . . .. Those only will, therefore, be received . . . who are of a proper school attending age, children between the ages of seven and fourteen, who are idiotic and who are not epileptic, insane nor greatly deformed."

The pioneers also made efforts to distinguish between more and less modifiable retardates. Generally, children with symptoms of severe brain injury and with multiple handicaps were not viewed as good prospects (e.g., Howe, 1848; Seguin, 1870). "The most favorable subjects for training, as a general thing, are those who enjoy good bodily health, who are free from epileptic and other fits, and whose heads are not enlarged" (Howe, 1852, p. 12). "The institution is not intended for epileptic or insane children, nor for those who are incurably hydrocephalic or paralytic, and any such will not be retained, to the exclusion of more improvable subjects" (Howe, 1852, p. 36). Seguin, after thirty years' experience, was reported to have said: "Idiots have been improved, educated, and even cured. Not one in a thousand has been entirely refractory to treatment, not one in a hundred who has not been made more happy and healthy. More than 30 per cent have been taught to conform to moral and social laws, and rendered capable of order, of good feeling, and of working like the third of a man. More than 40 per cent have become capable of the ordinary transactions of life under friendly control, of understanding moral and social abstractions, or working like two-thirds of a man; and 25 to 30 per cent have come nearer and nearer the standard of manhood, till some of them will defy the scrutiny of good judges, when compared with ordinary young men and women" (Seguin, as quoted by Carson, 1898, pp. 294-295).

It thus appears that only some retardates were seen to be proper candidates for institutional education, and this education was to consist mostly of the transformation of poorly socialized, perhaps speechless, and uncontrolled children into children who could stand and walk normally, have some speech, eat in an orderly manner, and engage in some kind of meaningful work. It should be kept in mind that perhaps this was equivalent to near-normality in a simpler society than ours today, and that from this fact may have grown the myth of the "curing" hopes of the early pioneers. However, translated to modern conditions, the pioneers appeared to have aspired to not much more than to what our best classes for the severely retarded aspire and frequently accomplish. The pioneers did not so much speak of making normals of "idiots," as of "educating the idiot."

The early pioneers held to a number of other ideas and practices of interest to our topic. One of the country's first institutions was privately operated by Wilbur. It was a "school . . . organized on the family plan. The pupils all sat at the same table with the principal, and were constantly under the supervision of some member of the family in the hours of recreation and rest as well as of training." "It was the belief of the managers that only a relatively small number of inmates could be successfully cared for in one institution. It was deemed unwise to congregate a large number of persons suffering from any common infirmity" (Fernald, 1893, p. 206; 209).

"Nearly every one of these early institutions was opened at or near the capitols of their various states, in order that the members of the legislature might closely watch their operation and personally see their need for the results of the instruction and training of these idiots" (Fernald, 1893, p. 209).

Indeed, the institutions were located in the very hearts of the community. The first public institution in the United States, established in Massachusetts by an 1848 act, was located for a time in a large rented residence in South Boston (Journal of Insanity, 1852, p. 27) " . . . in a crowded neighborhood" (Kerlin, 1885, p. 159).[5] Shortly thereafter, the first public institution of the State of New York was located in a " . . . large, spacious, airy, well arranged building on the Troy road, about two miles from the capitol . . ." (Journal of Insanity, 1852, p. 28). This building, too, was rented.

The rationale that retardates can be and should be removed from society in order to be trained for return to society, though of very questionable validity, is still alive today. We can still see this rationale implemented today, as when groups of adult community retardates are placed in an institution for 6 months of training under the Manpower Development and Training Act. However, it should be noted that the basic rationale for segregating the deviant for behavioral reshaping lacks adequate empirical foundation.

Essentially, making the deviant undeviant implied a developmental model. Furthermore, residential schooling was seen not merely as a privilege or worthy charity, but a right of the retardate and a duty of society. Again, Howe (1848, pp. 52-54) was a hundred years ahead of his time, and perhaps decades ahead of some of our contemporaries:

" . . . the immediate adoption of proper means for training and teaching idiots, may be urged upon higher grounds than that of expediency, or even of charity; it may be urged upon the ground of imperative duty. It has been shown, that the number of this wretched class is fearfully great, that a large part of them are directly at the public charge; that the whole of them are at the charge of the community in one way or another, because they cannot help themselves. It has been shown, that they are not only neglected, but that, through ignorance, they are often badly treated, and cruelly wronged; that, for want of proper means of training, some of them sink from mere weakness of mind, into entire idiocy so that, though born with a spark of intellect which might be nurtured into a flame, it is gradually extinguished, and they go down darkling to the grave, like the beasts that perish. Other countries are beginning to save such persons from their dreadful fate; and it must not longer be, that here, in the home of the Pilgrims, human beings, born with some sense, are allowed to sink into hopeless idiocy, for want of a helping hand.

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[5] For a picture of the Massachusetts School for the Feeble-Minded in South Boston, see page 114 of the Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, 1880, Vol. 5.

"Massachusetts admits the right of all her citizens to a share in the blessings of education, and she provides it liberally for all her more favored children. If some be blind or deaf, she still continues to furnish them with special instruction at great cost; and will she longer neglect the poor idiot,--the most wretched of all who are born to her,--those who are usually abandoned by their fellows,--who can never, of themselves, step up upon the platform of humanity,--will she leave them to their dreadful fate, to a life of brutishness, without an effort in their behalf?

"It is true, that the plea of ignorance can be made in excuse for the neglect and ill-treatment which they have hitherto received; but this plea can avail us no longer. Other countries have shown us that idiots may be trained to habits of industry, cleanliness, and self-respect; that the highest of them may be measurably restored to self-control, and that the very lowest of them may be raised up from the slough of animal pollution in which they wallow; and can the men of other countries do more than we? Shall we, who can transmute granite and ice into gold and silver, and think it pleasant work,--shall we shrink from the higher task of transforming brutish men back into human shape? Other countries are beginning to rescue their idiots from further deterioration, and even to elevate them; and shall our Commonwealth continue to bury the humble talent of lowly children committed to her motherly care, and let it rot in the earth, or shall she do all that can be done, to render it back with usury to Him who lent it? There should be no doubt about the answer to these questions. The humanity and justice of our rulers will prompt them to take immediate measures for the formation of a school or schools for the instruction and training of idiots.

"The benefits to be derived from the establishment of a school for this class of persons, upon humane and scientific principles, would be very great. The school, if conducted by persons of skill and ability, would be a model for others . . . . it would be demonstrated that no idiot need be confined or restrained by force; that the young can be trained to industry, order, and self-respect; that they can be redeemed from odious and filthy habits, and that there is not one of any age, who may not be made more of a man, and less of a brute, by patience and kindness, directed by energy and skill." "Now, we claim for idiots a place in the human family" (p. 17).

As the foregoing quotation and the one following below illustrate, the founding of the early institutions was accompanied by a pride, hope, and euphoria we can scarcely comprehend: "Let us now turn to the present: like Rome, we Americans can also boast of God-like men in our annals, and illustrious deeds on the historic page; as she had, we likewise are perhaps characterized by prominent faults, and by some compensating virtues." "Our eagles too have flown over a space equal to that which was traversed by those of Rome. To the Obelisks, and especially to the Cyclopean Coliseum we can show nothing equal or analagous. But we possess a class of institution scattered throughout our country, to which Rome was a stranger, and through which we have attained an exalted position that she never reached, or even had the soul to aspire unto" (attributed to an 1859 superintendent by DeProspo, 1966, p. 37).

Protecting the Deviant From the Nondeviant

As mentioned earlier, history appears to have wronged the founding fathers in ascribing to them the hope of "curing" large numbers of retardates. Our texts also seem to be partially mistaken in judging the early institutions to have failed to reach their objectives. Many residents were much improved under the tight and well-planned training regimens of the pioneers, and a substantial proportion of trainees did, indeed, return to the community.

About 26 per cent of residents discharged in Connecticut were believed to be self-supporting (Knight, 1879). In Kentucky, in 1884, alone, about 3 per cent of the residents of the state institution were placed into community employment (Kerlin, 1885, p. 166), and about 19 per cent of all new admissions were eventually discharged as self-supporting (Rogers, 1888, p. 102-103). "The experience of the past thirty years proves that, of those who are received and trained in institutions, 10 to 20 per cent are so improved as to be able to enter life as breadwinners; that from 30 to 40 per cent are returned to their families so improved as to be self-helpful, or at least much less burdensome to their people;" (Kerlin, 1888, p. 100). At Glenwood (Iowa), 68 of 195 residents were separated between 1885 and 1887, and 10 to 20 per cent of the residents appeared to attain eventual self-sufficiency in the community (Powell, 1887). "All of our schools for the feeble-minded have succeeded in sending out a goodly number of persons who are bearing bravely their share of the burden of life" (Rogers, 1888, p. 102).

There were, however, four problems:

1. There were bound to be failures with a certain proportion of residents.

2. For every resident successfully discharged, the statistical probabilities (due to the law of regression) were that his replacement would be less successful. It is hard to improve upon successful habilitation; it is much easier to fail thereafter.

3. Many residents who could have been partially habilitated had no place to return to, and thus, after some years, their continued

presence reduced turnover. Seguin referred to this as early as 1870 as a ". . . paternal, not yet legalized, arrangement" (p. 12), and Fernald (1893, p. 210) later described it as follows: "In the course of a few years, in the annual reports of these institutions we find the superintendents regretting that it was not expedient to return to the community a certain number of the cases who had received all the instruction the school had to offer." "It was found that only a small proportion . . . could be so developed and improved that they could go out into the world and support themselves independently. A larger number, as a result of the school discipline and training, could be taken home where they became comparatively harmless and unobjectionable members of the family, capable, under the loving and watchful care of their friends, of earning by their labor as much as it cost to maintain them. But in many cases the guardians of these children were unwilling to remove them from the institution, and begged that they might be allowed to remain where they could be made happy and kept from harm. Many of these cases were homeless and friendless, and, if sent away from the school, could only be transferred to almshouses where they became depraved and demoralized by association with adult paupers and vagrants of both sexes. It was neither wise nor humane to turn these boys and girls out to shift for themselves. The placing of these feeble-minded persons always proved unsatisfactory. Even those who had suitable homes and friends able and willing to become responsible for them, by the death of these relatives were thrown on their own resources and drifted into pauperism and crime. It gradually became evident that a certain number of these higher-grade cases needed life-long care and supervision, and that there was no suitable provision for this permanent custody outside these special institutions."

4. Many people, as evident in our textbooks, had misunderstood the objectives of the pioneers in expecting complete and rapid cures in large numbers, and interpreting any lesser accomplishment as tantamount to failure.

At any rate, with the perceived failure of the institution as a school, and the inability of many adult residents to adjust to the community, ideologies changed between about 1870 and 1880. Developmental attitudes degenerated into pity and charity, and as they did, the residential model changed from a developmental one to a pity model. The idea grew that retardates should be viewed as innocent victims of fate or parental sin, and that instead of schooling, loving care and protection should be bestowed upon them.

"In the race of life, where an individual who is backward or peculiar attempts to compete with those who are not, the disadvantages are so great that the graduate from the idiot asylum really has no chance to succeed. The capacity of the individual is not at fault; but the world is not full of philanthropic people who are willing to take the individual from the asylum and surround him with the proper guardianship which his case demands" (C. T. Wilbur, 1888, p. 110).

The term "School" began to disappear from the names of institutions, being replaced by the term "asylum." For example, in 1893, the

"Custodial Asylum for Unteachable Idiots" was founded at Rome, New York. "Give them an asylum, with good and kind treatment; but not a school." "A well-fed, well-cared for idiot, is a happy creature. An idiot awakened to his condition is a miserable one" (Governor Butler of Massachusetts, 1883, as quoted by Rogers, 1898, pp. 152-153). "It is earnestly urged that the best disposal to be made of this large class of the permanently disabled is to place it in custodial departments of institutions for the feeble-minded persons, in buildings judiciously remote from the educational and industrial departments, but under the same merciful system that inspires hope and help for the lowest of humanity, and under a broadly classified administration that will admit of the employment of the so-called moral idiot, thereby diminishing greatly the burden to the charitable and the taxpayer" (Kerlin, 1888, p. 100). "The question of unimprovability then being once established, the only practicable thing to do is to furnish a home where, amid cheerful surroundings, in accordance with the state of our Christian civilization, and in a manner consistent with an age of practical economy, the mediocre imbecile may lead a happy, harmless, and measurably useful life in assisting to care for his fellows" (Rogers, 1888, p. 103). "They must be kept quietly, safely, away from the world, living like the angels in heaven, neither marrying nor given in marriage" (Johnson, 1889, p. 319).

"Institutions have changed their character, largely to furnish a permanent residence with congenial surroundings for these unfortunates" (Wilmarth, 1902, p. 157). Illinois erected a "hospital building" for custodial purposes in 1885; a custodial department was installed in Iowa the same year; Connecticut made its first appropriation for such a building that year; and Pennsylvania built such a building in 1886 (Kerlin, 1886, pp. 289-294).

The Institution was no longer to be a school, but a shelter, an asylum of happiness, a garden of Eden for the innocent. What doubt there may have remained was largely dispelled by the close of the century: "Slowly but surely the conviction has become general, especially among the trustees and officers of institutions, that admission as a pupil of the training school should be but the first step to permanent care; that, with a few exceptions, so few that they may be disregarded in establishing a policy, all the pupils of the school, from the lowest to the highest grade, ought to be permanently retained in the safe, kindly, maternal care of the state. The above conviction is held by all who have expressed themselves publicly within the last few years in this country, excepting a few persons whose pecuniary interests seem in conflict with such a theory. It has been acted upon by the legislature of many states, whose laws have been changed by removing from the institution code the age limit of retention, and in some cases of acceptance." "A belief in the necessity of permanent care for all this defective class is professed by the superintendent of every state school for the feeble-minded in the United States today" (Johnson, 1898, p. 467).

The protective residential care model emphasized benevolent shelter, but it bore the seeds of three dangerous trends: (1) isolation, (2) enlargement, and (3) economization.

1. The retardate was to be moved out of society, in order to spare him the stresses he was believed incapable of bearing, and to provide him with protection from the persecution and ridicule of the nondeviant. The idea that the retardate must be protected from society, rather than vice versa, was well expressed by Kerlin (1884, p. 260): "The general grounds of the institution should be hedged or fenced to keep off improper instrusion, but be freely used by the inmates for walking exercise and work." H. B. Wilbur (1879, p. 96) recommended that institution grounds be fenced ". . . for the privacy of the inmates." Thus, institutions began to be removed from population centers and located in pastoral surroundings.

Writers of the period waxed rhapsodic over their own benevolence and drew an idyllic picture of the new trend: " . . . Here and there, scattered over the country, may be 'villages of the simple,' made up of the warped, twisted, and incorrigible, happily contributing to their own and the support of those more lowly,- 'cities of refuge,' in truth; havens in which all shall live contentedly, because no longer misunderstood nor taxed with extractions beyond their mental or moral capacity" (Kerlin, 1885, p. 174). " . . . God's innocent ones . . . " (Kerlin, 1886, p. 288) were to reside " . . . in harmony with the spirit of a progressive age and a Christian philanthropy" (Rogers, 1888, p. 105) in " . . . noble institutions of the times--those temples sacred to the restoration of fallen humanity, nearer Christ in his work than half the shrines dedicated in his name . . .." (Green, 1884, p. 269). These institutions were being " . . . sustained . . . by an abounding popular sympathy . . . " (Kerlin, 1886, p. 291) and were " . . . supplementing the work of the creator" (Pickett, 1885, p. 449).

If the institution was to be a Garden of Eden, it needed lands and gardens, and sure enough, an emphasis on gardening and farming developed. Thus, Osborne (1891) stated: "Ample acreage (not less than one acre per patient) will be provided for the proper seclusion of defectives from the stare of the idle and curious . . .." Kerlin (1885, p. 165) described the Connecticut institution as being " . . . beautifully situated on a large farm . . .", and by 1915, Schlapp (1915, p. 322) was able to say: "Most of our institutions are beautifully situated in the country." To this day, the phrase "happy farm" (much like "funny farm") is occasionally heard in reference to state hospitals and institutions for the retarded.

2. The idea developed that if there was to be special protective care, it would be advantageous to congregate larger numbers of retardates together. If institutions had to serve both an educational and custodial function, and if, for several decades, the educational department of an institution turned over more graduates to the custodial department

than the latter discharged (usually because of death), then it followed that institutions were under multiple pressure to grow. And grow they did. For instance, in Massachusetts, the first call by the trustees for substantial enlarging of the institution came in 1881, and this enlargement was to accommodate not only the "improvables" but also the "unimprovables" (Kerlin, 1885, p. 159). In Ohio, the transition from the smaller educational to the larger custodial institution was aided greatly by a disastrous fire in the year 1881. "Perhaps no trouble weighed more heavily upon the management than an effort to prevent the reconstruction of the building as an educational institution for feeble-minded children." The issue was "squarely met," and $400,000 was appropriated to construct the " . . . best built and the best appointed institution in the world . . ."--for 600 residents (Kerlin, 1885, pp. 163-164).

It is fascinating to trace the enlargement of institutions, and the fitful process of rationalization that accompanied it. First, to make room for rationalizing the enlargement, the pioneers' ideal of the small institution had to be destroyed. Paradoxically, this was done by accusing small institutions of "hospitalism": "It is the small institution against which may be pronounced the objection of moral "hospitalism." The large, diffuse, and thouroughly classified institution is another affair, and can be to its wards and employees as cosmopolitan as a city" (Kerlin, 1884, p. 262). "The growth of our institution to the proportion of a village, as earnestly urged by the superintendent, divides the board. The conservative element, which from the beginning has considered an institution of fifty or sixty children as the ideal, is still struggling against the inevitable. But thanks to Ohio, which continues to show us the way, in which all progressive States will follow" (Kerlin, 1885b, p. 369).

As usual, the irresistible trend toward enlargement was, at first, rationalized as being for the benefit of the resident. One detects the sentiment, present perhaps in all generations, that it is better for the deviant if he associates with his own kind: "We find that we must congregate them to get our best results. It is only from a large number that we can select enough of any one grade to make a group or class." "In order to have companionship, the most necessary thing in the education of all children, we must have large numbers from which to make up our small classes of those who are of an equal degree of intelligence" (Knight, 1891, p. 108). "We have also proved that we must have large institutions if we would get the best results; for, while the training of the imbecile must always depend mainly upon individual effort, yet the types are so diverse that it is only from considerable numbers that classes of a general degree of development are secured" (Knight, 1895, p. 153). "I believe that a large state institution is the best place for the feeble-minded or idiotic child" (Johnson, 1901, p. 410).

Others were more candid and advocated enlargement as a means of reducing cost, and during the pity period, the first arguments for the need of inexpensive care were heard. Wilbur had warned in 1880: "It will be readily seen that the cost of maintenance in such an establishment is a more important one than in the case of the educational institutions"(as quoted by Kerlin, 1885, p. 161). In about 1887, an act was passed in Pennsylvania which raised the number of state-supported residents from 400 to 500 while reducing the permissible per capita expenditure from $200 to $175 (Kerlin, 1888). "We have proved too, that in large institutions we can give employment to those adult imbeciles who are beyond what we call the 'school age' . . . As superintendents of institutions we are working out new methods in management, in economy and education . . ." (Knight, 1895, p. 561).

Rogers, in 1888 (p. 106), took one last look over his shoulders, as he and the field plunged ahead: " . . . to those who fear the growth of large and unwieldly institutions we only say that matters of that kind must be settled by the communities which are responsible for them. If this danger appears, stop the growth and build another institution, but do not warp the usefulness of any by a narrow comprehension of its functions."

By 1893, Fernald (p. 215) had observed a phenomenon familiar to us all: "Successive legislatures have been ready to enlarge existing institutions when they would not grant appropriations for establishing new ones." Thus, institutions changed from small intimate homes, for children counted in the dozens, to huge facilities for thousands of residents, and in 1893, Fernald could already refer to institutions as " . . . these immense households" (1893, p. 218).

3. Initially, as a constructive substitute for educational activities, increasing emphasis was placed on the retardate's working. Purportedly, the work was " . . . not for the value of the work itself, but for its value to the child" (Kerlin, 1885, p. 162). "The work-shop where several such industries are carried on provides occupation and relief from the depressing ennui of idleness, and at the same time fosters physical development and intellectual growth" (quoted from a Massachusetts report by Kerlin, 1885, p. 159). "With their daily tasks, their feeble minds directed, the time taken up in work or exercise, their days are spent in safety, pleasantness, and peace" (First Annual Report of the Trustees of the New York State Custodial Asylum for Feebleminded Women, as quoted by Kerlin, 1886, p. 290), " . . . the farm thus serving to provide healthful and attractive occupation for the stronger members of the institution . . ." (Reports from States, 1896, p. 37).

As usual, however, noble sentiments gave way to utilitarian practices and the economic value of work to the institution began to be stressed: " . . . the trained capacities of the stronger shall be made available for the aid of the weaker and for the diminution of public charge" (Kerlin, 1886, p. 269).

The economic emphasis, in the rural America of about 1880, implied adoption of agricultural pursuits, which, in turn, required land. The trend toward farming combined with the desire to protect the retardate resulted in locating institutions in isolated rural areas. For instance, establishment of the first farm colony (the "Howe Farm") in Massachusetts in 1881 (Kerlin, 1885; Fernald, 1902) became the occasion for moving residents from the institution in the heart of Boston out into the country, and to the periphery of society. Kansas opened its first state institution in 1881 near Lawrence, seat of the University, and Leavenworth, one of the important crossroads of the West. Three years later, the institution was moved far away onto a farm near Winfield (Kerlin, 1885, p. 169; Status of the Work, 1886, p. 451) because the land had been donated and to deal a blow to the University.

While we generally approve of an emphasis on work, we will see later in this essay the vicious turn this work emphasis took, and how so-called "institutional work peonage" (Bartlett, 1964; 1967) developed as residents became indispensable to the functioning of the institution.

Vail (1966) has classified the pity attitude as a special and subtle type of dehumanization. This may have been very insightful, since once the developmental attitude changed to pity, pity lasted only about 10-20 years, and was followed by a long period of brutalization. In our society, pity is usually extended to a person who is perceived as suffering. However, much of suffering, as we conceptualize it, implies that the sufferer should receive some kind of help, which may consume the time, money, emotional involvement or efforts of others. Suffering, by its very nature, thus makes a demand on a conscience developed in the Judeo-Christian tradition. This demand, in turn, may create resentment, especially if the sufferer does not "get well," and resentment may lead to brutalization. The fact that one of the most influential social organizations between 1874 and 1917 was the National Conference on Charities and Correction is of relevance, as it shows that the bestowers of pity and the controllers of menace had great commonalities.

Protecting the Nondeviant From the Deviant

Preceding and paralleling the education and pity periods, there had existed a current of negative attitudes toward the retarded. These attitudes, the three dangerous trends mentioned in the last section, and a new conceptualization of the retardate, combined to shape a new institutional model which is essentially the model embodied in most of our large, public institutions today.

The Early Indictment. The image of the retardate as a social menace grew in a subtle way. As early as the mid 1880's, the alarm was sounded: "But the State, adopting as its policy the protection in institutions of the defective classes, acquires a right of inquest into the causes generating this tremendous burden to the thrifty tax-payer, who must be protected from the rapacious social ills which deplete his own strength" (Kerlin, 1884, p. 262). An early president of the National Conference on Charities and Correction was later quoted by Wilmarth (1902, p. 160) as having said: "'My child, your life has been one succession of failures. You cannot feed and clothe yourself honestly: you cannot control your appetites and passions. Left to yourself, you are not only useless, but mischievous. Henceforth I shall care for you.'" "Is there anything more worthy the thoughtful attention of the statesmen of our land than to improve our methods of support of the weak ones so that we may add to it the needed element "control?" (Johnson, 1903, p. 252).

" . . . Can it be deemed wise, either for society or the defective himself, to turn him loose after some years of training to make his fight for existence on his own behalf?" "No amount of moral training during his school life can render him capable of judging points of morality for himself or make him proof against temptations to which his natural tendencies incline him to yield. The end will almost inevitably be that he will drift back into the care of the state, but through the gates of crime" (Dunphy, 1908, p. 331). "What in the beginning was a philanthropic purpose, pure and simple, having for its object the most needy, and therefore naturally directed toward paupers and idiots, now assumes the proportions of a socialistic reform as a matter of self-preservation, a necessity to preserve the nation from the encroachments of imbecility, of crime, and all the fateful consequences of a highly nervous age" (Barr, 1899, p. 208).

Fernald (1915, pp. 289-290) summarized the trend as follows: "During the last decade four factors have materially changed the professional and popular conception of the problem of the feeble-minded.

1. The widespread use of mental tests has greatly simplified the preliminary recognition of ordinary cases of mental defect and done much to popularize the knowledge of the extent and importance of feeble-mindedness.

2. The intensive studies of the family histories of large numbers of the feeble-minded by Goddard, Davenport, and Tredgold have demonstrated what had hitherto only been suspected, that the great majority of these persons are feeble-minded because they come from family stocks which transmit feeble-mindedness from generation to generation in accordance with the laws of heredity. Many of the members of these families are not defective, themselves, but these normal members of tainted families are liable to have a certain number of

defectives among their own descendants. The number of persons who are feeble-minded as a result of injury, disease, or other environmental conditions without hereditary predisposition is much smaller than had been suspected, and these accidental cases do not transmit their defect to their progeny.

3. The cumulative evidence furnished by surveys, community studies, and intensive group inquiries have now definitely proved that feeble-mindedness is an important factor as a cause of juvenile vice and delinquency, adult crime, sex immorality, the spread of venereal disease, prostitution, illegitimacy, vagrancy, pauperism, and other forms of social evil and social disease.

4. Our estimates of the extent and the prevalence of feeble-mindedness have been greatly increased by the application of mental tests, the public school classes for defectives, the interpretation of the above-mentioned antisocial expressions of feeble-mindedness, and the intensive community studies. Goddard believes that at least 2 per cent of school children in the first five grades are mentally defective. It is conservative to say that there are at least four feeble-minded persons to each thousand of the general population.

There are reasons for believing that feeble-mindedness is on the increase, that it has leaped its barriers, so to speak, as a result of changed conditions of civilization" (Fernald, 1915, pp. 289-290).

One might add here that a fifth point was the belief that the retarded were reproducing at a more prolific rate than the nonretarded, and might therefore "outbreed" the latter.

The Peak of the Indictment. As time passed, the social indictment of the retardate grew more direct, severe, and shrill. Barr said: "Of all dependent classes there are none that drain so entirely the social and financial life of the body politic as the imbecile, unless it be its close associate, the epileptic" (1902, p. 163). Butler (1907, p. 10) added: "While there are many anti-social forces, I believe none demands more earnest thought, more immediate action than this. Feeble-mindedness produces more pauperism, degeneracy and crime than any other one force. It touches every form of charitable activity. It is felt in every part of our land. It affects in some way all our people. Its cost is beyond our comprehension."

"When we view the number of the feeble-minded, their fecundity, their lack of control, the menace they are, the degradation they cause, the degeneracy they perpetuate, the suffering and misery and crime they spread,--these are the burden we must bear" (Butler, 1915, p. 361). "For many generations we have recognized and pitied the idiot. Of late we have recognized a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace to society and civilization; that he is responsible to a large degree for many, if not all, of our social problems" (Goddard, 1915, p. 307). " . . . We preach . . . that . . . the feeble-minded at large unguarded are a menace to the community" (Cornell, 1915, p. 322). " . . . Those unfortunate members of society who fall so far short of the line of normal mentality as to be an inherent social menace." " . . . It is among this group that there flourishes the real peril to the mental and moral stamina of our nation." "The problem itself is the most serious facing the country today" (Schlapp, 1915, pp. 320-321).

Bullard (1910, pp. 14-15), in the strongest statement of indictment of retarded women, warned: "Girls of the classes described must be cared for by the state . . . . There is no class of persons in our whole population who, unit for unit, are so dangerous or so expensive to the state. This excepts no class, not even the violently insane. They are much more dangerous and expensive than the ordinary insane or the ordinary feeble-minded or the ordinary male criminal." He (1910, p. 320) added: "There is probably no class of persons who are more fitted and more apt to spread disease and moral evil than these girls," and "One evil girl may corrupt a whole village." "A single feeble-minded girl among a group of young boys becomes a plague-spot, the consequences of which are frightful" (Butler, 1915, p. 358).

It can be noted from the statements quoted above that while male retardates were seen as a "menace of the greatest magnitude," females were seen as even more dangerous, if this is possible: "It is certain that the feeble-minded girl or woman in the city rarely escapes the sexual experiences that too often result in the birth of more defectives and degenerates" (Fernald, 1912, p. 90). " . . . Imbecile girls and women everywhere [are] an easy prey to the wiles and lust of brutal men, . . ." (Carson, 1898, p. 296). "Few of these girls permanently escape, unless they are specially cared for by wise and understanding people. Their care demands unceasing vigilance and constant thought, which can rarely be properly exercised outside of an institution. As a fact, these girls--unless cared for permanently in an institution--usually become immoral or are led away to make bad marriages. In either case their children are apt to be mentally defective, with more or less pronounced animal instincts, diseased and depraved, a curse and menace to the community. This goes on constantly increasing unless we take means . . . to prevent the production of children. The evil that one feeble-minded woman can cause through the production of feeble-minded children is incalculable. It has often been plainly stated: statistics have been carefully compiled and the results are too well known to need repetition before this Conference" (Bullard, 1910, pp. 333-334). "Feeble-minded women are almost invariably immoral, and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves. The feeble-minded woman who marries is twice as prolific as the normal woman" (Fernald, 1915, pp. 90-91). Schlapp (1915, p. 323) referred to " . . . the feeble-minded pregnant woman who is, naturally, unmoral." "The debasing and demoralizaing influence of an unrestrained feeble-minded woman in a community is beyond the comprehension of the uninformed" (Butler, 1907, p. 2).

Fernald was one of the strongest indictors: "And pauperism breeding other paupers, what is it but imbecility let free to do its mischief?" "The tendency to lead dissolute lives is especially noticeable in the females. A feeble-minded girl is exposed as no other girl in the world is exposed" (Fernald, 1893, p. 212). Later, (1904, p. 383) he said: "It is well known that feeble-minded women and girls are very liable to become sources of unspeakable debauchery and licentiousness which pollutes the whole life of the young boys and youth of the community. They frequently disseminate in a wholesale way the most loathsome and deadly diseases, permanently poisoning the minds and bodies of thoughtless youth at the very threshold of manhood. Almost every country town has one or more of these defective women each having from one to four or more illegitimate children, every one of whom is predestined to be defective mentally, criminal, or an outcast of some sort.

"The modern American community is very intolerant of the presence of these dangerous defectives with the desires and passions of adult life, without control of reason and judgment. There is a widespread and insistent demand that these women be put under control" (Fernald, 1904, p. 383). "The adult males become the town loafers and incapables, the irresponsible pests of the neighborhood, petty thieves, purposeless destroyers of property, incendiaries, and very frequently violators of women and little girls" (Fernald, 1904, p. 383). "The social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. The great majority ultimately become public charges in some form. They cause considerable sorrow at home and are a menace and danger to the community." "Every feeble-minded person, especially the high-grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies. The unrecognized imbecile is a most dangerous element in the community." "It has been truly said that feeble-mindedness is the mother of crime, pauperism and degeneracy. It is certain that the feeble-minded and the progeny of the feeble-minded constitute one of the great social and economic burdens of modern times" (Fernald, 1915, pp. 190; 91; 92).

The peak of the indictment of the retardate was reached between 1908 and 1915, and was embodied in three important documents:

1. The 1908 British Royal Commission Report, which became very influential in this country: "The evidence points unmistakenly to the fact that mentally defective children often have immoral tendencies; that they are greatly lacking in self-control; and moreover are peculiarly open to suggestion, so that they are at the mercy of bad companions."

"Many competent observers are of the opinion that if the constantly or recurring fatuous and irresponsible crimes and offenses of mentally defective persons are to be prevented, long and continuous detention is necessary. The experience of the prison authorities fully confirms this opinion. From the earliest age, when they appear before the magistrates as children on remand or as juvenile offenders, until and throughout the adult period of their lives, the mentally defective, at first reprimanded and returned to their parents, then convicted and subjected to a short sentence and returned to their parents, and then later continually sentenced and resentenced and returned to their parents or friends until, for crimes of greater gravity, they pass through the convict prisons, are treated, as this reiterated evidence shows, without hope and without purpose, and in such a way as to allow them to become habitual delinquents of the worst type and to propogate a feeble-minded progeny which may become criminal like themselves. This, as has been said, is an 'evil of the very greatest magnitude.' The absolute and urgent necessity of coping with it is undeniable" (Royal Commission Report of 1908, quoted in Davies, 1923).

2. Fernald (1912) wrote a damning indictment of the retarded in his famous address on "The Burden of Feeble-Mindedness," a burden he had earlier (1893, p. 213) called "disgusting."

3. Bullard (1910) wrote an incredible diatribe about the particular immorality and menace of retarded women.

In weighing the influence of some of the indictors quoted in preceding and subsequent sections, let the reader be reminded that the following 25 persons had been, or became, presidents of what is now the American Association on Mental Deficiency: Wilbur, Stewart, Powell, Fish, Knight, Carson, Rogers, Kerlin, Osborne, Wilmarth, Barr, Dunlap, Johnson, Polglase, Murdoch, Smith, Bullard, Goddard, Emerick, Watkins, and Anderson; Bernstein, Fernald, Johnstone, and Wallace held the presidency twice. Johnson had also been president of the National Conference on Charities and Correction, as well as its general secretary for many years. This latter organization was perhaps the major vehicle of the indictment, since it was a major forum for indictment speeches and papers, and since it encompassed those professionals most intimately concerned with social processes, such as social workers, sociologists, legal and law enforcement personnel, psychiatrists, psychologists, public health and immigration workers, and officials from all levels of government.

Dehumanizing and Brutalizing Elements of the Indictment. The indictment contained some ominous notes. Streeter (1915, p. 340) said: " . . . in feeble-mindedness lies the tap root of most of our social problems; the only effective radical way to deal with these problems, is to strike at this tap root with the strong ax of prevention." Barr (1902a; 1902b), a very influential past president of what is now the American Association on Mental Deficiency, issued an "Imperative Call of Our Present to Our Future," followed by an address entitled

"The Imbecile and Epileptic Versus the Taxpayer and the Community." The title of a book by Crookshank in 1924 was enough to drive a shudder down anyone's spine: "The Mongol in Our Midst."

Where we, today, speak of combatting mental retardation, as in the President's Panel "National Plan To Combat Mental Retardation," phrases with menacing overtones were used in the alarmist period, as when Johnson (1898, p. 471) spoke of "stamping out" idiocy and imbecility. That this was more than a figure of speech became clear 2 years later, when he stated: "I do not think that, to prevent the propagation of this class it is necessary to kill them off or to resort to the knife; but, if it is necessary, it should be done" (Johnson, 1901, pp. 410-411). Alexander Johnson, past president of the National Conference on Charities and Correction, and of what is now the American Association on Mental Deficiency, was one of the most influential figures in the social action field of the era.

One gentleman from Massachusetts, in 1885, was reported to have called for the same solution to the problem of feeble-mindedness as that which had been "applied theoretically and also practically to the Indian question" (Conf. on Charities and Correction, 1888, p. 396), and Taft (1918, p. 545) ominously referred to a " . . . final . . . solution . . . ", a term that would come into its full meaning 20 years later.

In any society that places high value on intelligence and achievement, there is probably a predisposition to brutalize and dehumanize the inadequate deviant. When the deviant is seen as not only inadequate but also as a menace, latent dehumanization becomes overt. It therefore does not surprise us that during the alarmist period the retardate was dehumanized in both word and deed.

Analogies based on examples from the animal, vegetable, and mineral world are sometimes offered to explain a point about retardation. Often, such an analogy is ill-chosen at best; at worst, it reveals that the person using the analogy perceives the retarded as subhuman. Some examples of ill-chosen word pictures used during the indictment period follow. Kerlin (1884, p. 249) said of a mental retardate: "With his great luminous, soft, jet eyes, he reminds one of a seal." Fernald (1915, p. 291) observed: "We now have state commissions for controlling the gypsy moth and the boll weevil, the foot-and-mouth disease, and for protecting the shell-fish and wild game, but we have no commission which even attempts to modify or control the vast social, moral and economic forces represented by the feeble-minded persons at large in the community." Davenport (quoted by Fernald, 1915, p. 290) moved from "unfit animal strains" to "weak strains" to the "feeble-minded" in the pace of two sentences.

Simultaneous reference to animal breeding and to reproduction of retardates abounded. Brewer (1895, p. 467) referred to retardates as " . . . this breed of men" being a " . . . poor breed of stock." Barr (1902, p. 163) had this to say: "We are very careful as to the breeding, inbreeding, or non-breeding of our flocks and herds and beasts of burden; but we allow epileptics and irresponsible imbeciles to taint pure stock or to reproduce their kind unmolested without intervention." The important role of a national association of cattlemen in the study of prevention of retardation is noteworthy and will be touched upon again later in this essay. Wines (1889, p. 321; also quoted by Bicknell, 1896) said about retarded workers: "Many of them are capable of being made useful to a large extent even though they may be unable to talk. I have seen idiots who were useful on a farm, for instance, who could not speak a word. Is not a mule valuable on a farm? Yet he cannot talk." One might have considered such an analogy merely unfortunate, had he not abrogated the human capacity for suffering from a retardate in a second comparison to animals (p. 323). In describing a retarded woman chained by the neck to a dog's running-wire in the yard, he denied that she was suffering because "she was a mere animal, well cared-for as an animal." Nosworthy (1907) probably expressed latent sentiments most honestly when, in all seriousness, she raised the question whether the feeble-minded constitute a separate species, and then designed a study to investigate this matter.

Humans can be dehumanized even below the animal and vegetative level, as when they are called "waste products" (Barr, 1902, p. 165; Anderson, 1918, p. 537) or "by-products" (MacMurchy, as quoted in Murdoch, 1909, p. 66; Southard, 1915, p. 316). Southard continued to ask: " . . . it becomes a question with us, what to do with these waste materials."

Concern With Prevention. It should be obvious from reading the indictment that retardation was considered to be hereditary. Some quoted statements follow: "We have only begun to understand the importance of feeble-mindedness as a factor in the causation of pauperism, crime and other social problems. Hereditary pauperism, or pauperism of two or more generations of the same family, generally means hereditary feeble-mindedness. In Massachusetts there are families who have been paupers for many generations. Some of the members were born or even conceived in the poorhouse" (Fernald, 1915, p. 91). "No feeble-minded mother will ever have a child absolutely normal in every respect" (Johnson, 1908, p. 333). "Feeble-mindedness is hereditary and transmitted as surely as any other character" (Goddard, 1912, p. 117). " . . . In two-thirds of the cases feeble-mindedness is caused by feeble-mindedness . . . " (Goddard, 1915, p. 308). "It is possible that a real eugenic survey of a given locality might show that 90% of the feeble-mindedness in that locality was contributed by 5% of the families in that community" (Fernald, 1915, p. 294). "Degeneracy, once permitted to invade a lineage, can never be wholly eradicated; lessened materially, and even reduced to a minumum it may be, but sooner or later, in one generation or another, a defective is bound to appear." " . . . There are at least 328,000 mental and moral defectives at large, perpetrating, unrestrained, the defilement of the race." " . . . Imbecility will breed imbecility and where there is a trace of feeble-mindedness in a family it is sure, sooner or later, to reappear, the defective 'germ plasma' producing an abnormal" (Barr, 1915, pp. 361-363). "We must come to recognize feeble-mindedness, idiocy, imbecility, and insanity as largely communicable conditions or diseases, just as the ordinary physician recognizes smallpox, diptheria, etc., as communicable" (Sprattling, 1901, p. 409). When Goddard (1912, pp. 283-284) was asked whether feeble-mindedness could not be the result of poverty and malnutrition, he said: "There is not the slightest evidence that malnutrition, or any environmental condition can produce feeble-mindedness" (Goddard, 1912, pp. 283-284).

A logical conclusion of the foregoing line of reasoning was that aside from euthanasia, only prevention of reproduction of retardates could reduce the number of retardates: "At least, let us wipe out the stain of legalizing the production of idiocy, imbecility, insanity, and crime" (Knight, 1898, p. 308). "This national body of charity workers, together with its associate bodies, has done a mighty work in the past score of years in helping to project the establishment of these institutions; but its helping hand must ever be extended, and its heart and soul be strong in purpose, until legislation shall put in force necessary preventive measures that will stop the increase and wipe out the degeneracy of the past, until humanity shall recognize the need of pure living and right purpose" (Polglase, 1901, p. 190).

"The one effective way to diminish the number of the feeble-minded in future generations is to prevent the birth of those who would transmit feeble-mindedness to their descendants." "Indeed, the results of eugenic research are so impressive that we are almost convinced that we are in possession of knowledge which would enable us to markedly diminish the number of the feeble-minded in a few generations if segregation or surgical sterilization of all known defectives were possible" (Fernald, 1915, p. 290).

Barr, in 1915 (p. 361) wrote an article entitled "The Prevention of Mental Defect, The Duty of the Hour," which began: "That the prevention of the transmission of mental defect is the paramount duty of the hour, is a truism not to be questioned." The article contained the following memorable lines: " . . . One cannot fail to recognize the necessity for the enforcement of measures which experience has demonstrated as absolutely needful steps toward prevention, viz: The separation, sequestration and asexualization of degenerates . . ." (1915, p. 364).

Other writers added: "The successful control of amentia is the most imperative of public duties." " . . . Conserve the mental virility and moral integrity of the race" (Schlapp, 1915, pp. 328; 321). "The present generation is the trustee for the inherent quality as well as for the material welfare of future generations" (Fernald, 1915, p. 295). " . . . We absolutely cannot afford to wait" (Knight, 1898, p. 307).

Much study was given to the means of prevention. Private and public study and action groups proliferated. In 1903, there existed a "Committee on Colonies For and Segregation of Defectives" of the National Conference on Charities and Correction. By 1915, seven states had public commissions (Schlapp, 1915) much like our governors' committees today. Several other states had unofficial commissions, and several cities had commissions much like today's mayor's committees. In Philadelphia in 1916, there was headquartered a national organization, entitled "The Committee on Provision for the Feeble-minded," that had as its purpose " to disseminate knowledge concerning the extent and menace of feeble-mindedness and to suggest and initiate methods for its control and ultimate eradication from the American people" (as quoted by Johnstone, 1916, pp. 206-207). This committee was instrumental in giving 1,100 lectures to about 250,000 people; in establishing institutions in nine states that had none; in increasing the number of existing institutions in five states; and in extending the sizes of existing institutions in four states (Davies, 1930).

One of the more influential study groups was the Eugenics Section of The American (Cattle) Breeders Association, which, curiously, later became the American Eugenics Society and the sponsor of the respected contemporary journal Eugenics Quarterly. This group issued a well-known report (summarized by Van Wagenen, 1914) that considered 10 possible measures, judging only two to be practical: sterilization, and segregation of those retardates capable of reproduction. In general, there was a " . . . keen interest in everything pertaining to the mentally deficient both in Europe and in this country. The realization of the vast extent of mental defect, the inexorable requirements of the modern graded school systems with the study of the resulting retardation, the popular application of the Binet and other psychological tests, are some of the causes of this interest. Mental deficiency has become a subject of vital and pressing significance to physicians, psychologists, teachers, court officials, social workers, and legislators. The subject is being studied from medical, biological, pedagogical, psychological, sociological, economic, and eugenic points of view. The field of mental defect has been so broadened and extended as to include all the professional disciplines" (1913, cited by De Prospo, 1966, p. 38).

Belief in the genetic causation of retardation had some convenient aspects. By proposing that most social problems would be solved if the poorer members of society would stop having children, one could feel freed from a sense of responsibility for bad social condition. Furthermore, one was relieved from the worry of the effects of slum conditions upon children, if one could believe that many such children were genetically inferior to begin with. It is probably no coincidence that the indictment period overlapped with periods during which Social Darwinism and laissez-faire socio-economic policies were prominent.

Failure of Preventive Marriage Laws. In order to understand how institutions for the retarded in the United States developed as they did, we must understand the failure of alternative provisions.

During the indictment period, the only hope seen was in the prevention of procreation of individuals likely to produce retardates. Three methods suggested themselves: forbidding the mating of retardates by law; preventing procreation, of those retardates who might mate, by sterilization; and preventing both mating and procreation, by means of segregation.

Outlawing of procreation was attempted early in the alarmist period. In about 1895, House Bill 681, containing the following provision, was passed in Connecticut:

"Every man who shall carnally know any female under the age of forty-five years who is epileptic, imbecile, feeble-minded, or a pauper, shall be imprisoned in the State prison not less than three years. Every man who is epileptic who shall carnally know any female under the age of forty-five years, and every female under the age of forty-five years who shall consent to be carnally known by any man who is epileptic, imbecile, or feeble-minded, shall be imprisoned in the State prison not less than three years" (Beedy, 1895, p. 468). Similar bills were soon passed, and some of these bills are still on the books today. A national marriage law to prohibit marriage to the feeble-minded and insane was proposed as early as 1897 by Wells (1897), and was widely supported. In 1899, what is now the American Association on Mental Deficiency appointed a committee to explore cooperation with the National Conference on Charities and Correction, the Prison Congress, the Medico-Psychological Society, and other bodies that might be interested in supporting restrictive marriage laws (J. Psycho-Asthenics, 1899, 3, pp. 194-195). By 1900, Wilmarth (1902, p. 156) had this to say: "There are only two remedies for the abatement of this evil in the class of which we speak to-day. The seclusion of feeble-minded and epileptic adults, especially females between the ages of fifteen and forty-five who are liable to become willing subjects to man's rascality, and the passing of such laws as shall prevent the marriage of defectives, or the living together as man and wife of any one with a defective person."

The ineffectiveness of marriage laws was soon recognized: "Restrictive marriage laws are no doubt advisable, but . . . unavailing because the unfit reproduce their kind regardless of marriage laws" (Murdoch, 1913, pp. 36-37). Alas, sex, even less than alcohol later on, was not easily outlawed. However, sterilization suggested itself as a reasonable alternative.

Failure of Preventive Sterilization. Sterilization, or as it was also called, asexualization and unsexing, was apparently first advocated to a significant degree in the mid-1890's. Like virtually all administrative measures which the nondeviant design to manage the deviant, sterilization was often rationalized as being to the retardate's advantage. Barr (1902) called for " . . . invoking the aid of surgical interference to secure . . . greater liberty, therefore, greater happiness to the individual" (p. 5).

In 1902, Nicholson (p. 495) ended the discussion of papers on the "feeble-minded and epileptic" at the Detroit National Conference on Charities and Correction by stating that "the only way to get rid of such imbeciles is to stop raising them." A more direct tact was taken by Perry (1903, p. 254): " . . . It would now be well to prepare our several states to call to our assistance the surgeon's knife to prevent the entailing of this curse upon innocent numbers of yet unborn children." Barr asked: " . . . Knowing the certain transmission of such taint, how can one fail to appreciate the advantage of prevention over penalty, or to recognize as the most beneficient instrument of law the surgeon's knife preventing increase. And why not? We guard against all epidemics, are quick to quarantine small-pox, and we exclude the Chinese; but we take no steps to eliminate this evil from the body social" (1902, p. 163).

It was soon recognized that sterilization, in order to reduce the number of retardates to an appreciable extent, had to be compulsory, and such laws were passed throughout the nation and generally upheld by the courts.[6] However, it was also found that sterilization laws were only slightly more enforceable than mating laws; that not all retardates were reached by the laws; and that sterilization would not prevent as many cases of retardation as had been thought: "Compulsory surgical sterilization of all defectives is proposed as a radical method for preventing the hereditary transmission of feeble-mindedness. At least six states have passed laws authorizing or requiring this operation. In no state, however, has this remedy been applied on a large scale. There are many objections to this plan. The friends of the patients are not willing to have the operation performed. The normal 'carriers' of defect would not be affected. The presence of these sterile people in the community, with unimpaired sexual desire and capacity would be direct encouragement of vice and a prolific source of venereal disease. Sterilization would not be a safe and effective substitute for permanent segregation and control" (Fernald, 1915, pp. 95-96).

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[6] An apparently widely held view was stated by Taylor (1898), who reasoned that if procreation was rendered impossible by surgery, there would be no further value in preserving the sexual instinct of the retardate. Since much harm was seen to result in the cultivation or even retention of this instinct, Taylor recommended that it would be just as well " . . . to remove the organs which the sufferers are unfit to exercise normally, and for which they are the worse in the unnatural cultivation or use" (p. 81). Thus, for males, castration was widely preferred over vasectomy (Cave, 1911; Van Wagenen, 1914). In one stroke, it not only accomplished sterilization; it also eliminated "sexual debaucheries" (Cave) and masturbation (Van Wagenen), and perhaps even improved "the singing voice" (Barr, 1905) and diminished epileptic seizures (Barr, 1904). Sometimes, castration was performed " . . . after exhausting every other means . . ." as a " . . . cure for masturbation," even without a perceived need for sterilization (Reports from States, 1895, p. 348). By 1914, sterilization was used not only for eugenic but also for penal reasons, sometimes in addition to a prison sentence. The courts upheld this measure as constituting neither cruel nor unusual punishment for certain crimes (Van Wagenen). In cases where vasectomy was performed, retardates did "not require an anesthetic since all that is required is to cut the *vas defrens*" (Risley, 1905, p. 97).

"Sterilization of the feeble-minded is logically the solution for the problem of prevention of propagation of the mentally unfit where feeble-mindedness is due to heredity. Practically, despite legislation, it has never worked because it is purely an intellectual remedy. It has never considered the prolonged period of preparation and education necessary to change deep-seated primitive attitudes. There may come a time when sterilization of the unfit will be worked into our program, but it will be only when the general level of enlightenment on social problems is materially raised by slow growth" (Taft, 1918, p. 545). "The sterilization of feeble-minded is now universally acknowledged to be impracticable, principally because the line of demarcation between feeble-mindedness and normality is not definite, because the hereditary influence in this field has not been quantitatively determined, because the operation is dangerous, the idea more or less revolting and, possibly, because it is not in consonance with the religious thought of a certain portion of the community. Sterilization, therefore, need not be further discussed at this time" (Cornell, 1915, p. 338).

Failure of Preventive Segregation. Once mating laws, sterilization, and other measures had been recognized as ineffective or unacceptable in preventing the spread of the retardation menace, only segregation (Fernald 1915 called it "strict sexual quarantine") remained, and it was advanced with utmost vigor by the workers in the field. First, of course, it had to be rationalized to be, at least in part, for the welfare of the retardate. An editorial in the Journal of Psycho-Asthenics in 1899 asked: "Of what is a high-grade imbecile deprived on entering a well-conducted institution?", and concluded he would only be deprived of deprivation. Winspear (1895, p. 163) reasoned as follows: "A moment's thought, and the fact is plain that unprotected feeble-minded women of full physical development are in constant danger themselves, and are always a menace to society, - a two-fold reason why custodial care for this class should be the paramount idea in the State's provision for the feeble-minded. Thus their proper care and protection is a twice blessed charity, in that it blesses the recipient of the State's bounties and blesses society by the removing of a great evil therefrom."

More direct arguments included the following: "Shall we turn these irresponsibles loose to undo the work of the past and redouble that of the future? Surely history would not write our names among the wise." (Barr, 1899, p. 211) " . . . I think we need to write it very large, in characters that he who runs may read, to convince the world that by permanent separation only is the imbecile to be safe-guarded from certain deterioration and society from depredation, contamination and increase of a pernicious element" (Barr, 1902, p. 6). "But all of them whether able of productive labor or wholly helpless, or of any grade between these extremes, ought to be permanent wards of the state so long as they shall live" (Johnson, 1901, p. 411).

In 1905, retarded adult males were characterized in the Maine Senate as "town loafers and incapables," "petty thieves," "incendiaries," and "violators of women and little girls"; females were described as sources of "unspeakable debauchery" which "pollute the whole life of young boys" and who "have illegitimate children every one of whom is predestined to be defective mentally, criminal or an outcast of some sort." Such individuals were to be placed in an institution, and the institution, in turn, was to be placed in an isolated spot. These measures were to save the communities of the state of Maine from "terrible menace" and "economic burdens" of the feeble-minded whose "uncontrolled life and movements threatened great harm to society" (quoted by Levinson, 1960).

"The only just and humane and civilized way of stopping the transmission of defectiveness is by segregation" (Johnson, 1908, pp. 333-334). "Every effort must be made to get these defectives out of society . . ." " . . . the degeneracy must cease here" (Johnstone, 1904, pp. 66, 65).

Consistent with the proposal advanced earlier that retardation should be treated as a communicable disease Murdoch (1909) gave a paper entitled "Quarantine Mental Defectives." Johnstone (1904, p. 66) called for a " . . . quarantine of this social disease . . . ."

"On the most important proposition of all--who gets born--last year Governor Foss vetoed an increased appropriation for our second school for the feeble-minded. This year, however, provision was made for two new cottages, which will hold two hundred inmates, and cut off by, perhaps, half that number of source of supply of the unhappy and unfit among future generations. The righteous have sworn the segregation of all the feeble-minded for 1925" (Reports from States, 1912, p. 525).

Not only were the retarded to be segregated from society, but even within institutions, men and women were strictly segregated, almost to a paranoid and bizarre degree: "The institution that places . . . boys and girls anywhere near each other . . . will never do its part in the work of preventing feeble-mindedness in the community." "The institution superintendent who allows feeble-minded boys and feeble-minded girls to work together even in the garden, is running the risk of a second generation of illegitimate feeble-minded children" (Cornell, 1915, pp. 333-334).

If it was difficult to keep men and women apart within an institution, then separate institutions for the sexes might be the answer, and a number of such institutions were maintained or built: "Custodial care for feeble-minded women of full physical development, in distinctly separate institutions, which was at first considered by many a doubtful experiment, has proved a grand success, and should be followed by every other state in this country" (Winspear, 1895, p. 161).

The extreme in segregation was advocated by Barr who proposed the establishment of one or more national institutions or reservations (Barr, 1897; 1899; 1902; Dunlap, 1899) similar to the management of another large group of deviants in America, viz., the Indians: "The National government has provided for the Mute, the Negro, and the Indian--then, why not for this branch of population increasing as rapidly as they, and becoming yearly more inimical to national prosperity. A reservation set apart, affording facilities for agricultural pursuits as well as all the varied industries of a town, would provide an outlet for the surplus population of our institutions, to find there a home with definite life aims constantly realized. Such a colony, under such restrictions and protective care as our experience has proven is essential, a congregate number of institutions, so to speak . . ." (Barr, 1897, p. 13). "Protected from the world and the world from them, these children of the nation, instead of as now, its standing peril, would be a constant object lesson, at once a reproof and a warning to guide us to that 'statlier Eden of simpler manners, purer laws' which the twentieth century shall usher in" (Barr, 1899, p. 212).

Workers in the field were, at times, rather unrealistic. They exhorted the public to marry on a eugenic rather than emotional basis, and to forego marriage altogether if presumably inheritable detrimental traits were observed in their families. Similarly, some workers appealed to parents to institutionalize their children voluntarily: "Greater efforts must be made to have the great public know of the defectives, so that we shall not be accused of having axes to grind when we ask for more provision for them. Institution men must encourage visits, give out information and indeed, conduct a campaign of education, so that in the first place the unwillingness of parents to send their children shall be changed to eagerness, and then will follow the demands of public opinion and the concessions of legislatures" (Johnstone, 1906, p. 237).

At the end of the founding period, legislatures had been asked to permit residents to stay. As late as 1902 (Wilmarth, 1902), discharges from institutions were easy and informal. However, the tone changed during the alarmist period, and increasingly, laws and rules mandated legal and quasi-permanent commitments rather than voluntary and temporary ones: " . . . parents brought their children after a commitment by a local magistrate and in many cases subsequently tormented the superintendent of the institution by demands for their release. The superintendent was so harassed that he, himself, made a rule that he would receive no children unless they were committed to him by the courts, so that the state was made a legal guardian of the children in the institution. We are happy to say that this principle was afterwards embodied in an act of the legislature, in effect October, 1914, which provided that all admissions and discharges from the state institution at Spring City should be by court commitment" (Cornell, 1915, p. 332).

Since segregation was for the protection of society, it was only logical that commitments should be compulsory: "Segregation does not mean the opening of a boarding home by the state in which parents may place their feeble-minded children, have them trained by much labor, to the point where they become dangerous to the community if allowed at liberty, and then remove them and turn them loose" (Cornell, 1915, pp. 331-332). Johnstone (1908a) recommended that admission of "degenerates" require a trial and an indeterminate sentence. Release would also be only by trial, although little need for such trials was seen: "The only possible reason we can urge for their being set free is a sentimental one" (p. 114).

Apparently, Illinois was the first state to require court commitments, as of 1915 (Harley, 1917), to the exclusion of all other types of admission. Laws of this nature were criticized, not on legalistic or humanistic grounds, but because they might discourage parents from admitting their children (e.g., Carson, 1906).

One is left with the distinct impression that sensing the impending failure to segregate all the retarded, workers in the field vented their frustration by striving to increase the degree of segregation of those retardates already in their custody. Also, the fact that retarded residents had been released into the community both before and after the indictment period would appear to indicate that the decline of successful rehabilitations early during the indictment was an artifact of institutional policy. In other words, institution personnel did not release residents because they did not believe that residents could or should succeed. For instance, until 1967, retardates in Nebraska gained entrance to the state institution only by court commitment; once committed, they could, until 1963, only be released if they were sterilized or otherwise incapable of reproduction. To this day (1968), the law requires that release be preceded by a time-consuming expensive review by a sterilization board.

Our historical review approaches another critical point. We must now consider that the professionals in the field were thoroughly convinced that the survival of society required that the largest number of retardates be institutionalized as fast as possible. "Assuredly, if we are to rise to the responsibility of the times, to grapple with this enemy one hundred thousand strong, which enters all homes alike and threatens the very life-blood of the nation, we must enlarge our borders and extend our operations. We need space, and yet more space, and who than we better fitted to claim it?" (Barr, 1897, pp. 12-13). Here, however, the professionals encountered limitations in funding of institutions, and the public and legislatures were not channeling additional funds as fast as the professionals thought they should. "The public, while liberal in all its charities, demands that the funds so appropriated should be wisely and economically expended, and that the cost should be kept as low as possible, consistent with the best methods of carrying on the work" (Wilmarth, 1902, p. 152). "Our taxpayers are already groaning under the burden of caring for the actual imbecile and the epileptic" (Fernald, 1908, p. 116).

First, there was an attempt to convince the public that financial support of institutions would save money in the long run: "This special care is now recognized as not only charitable, but economical and conservative. Each hundred dollars invested now saves a thousand in the next generation" (Fernald, 1893, p. 221).

"As a simple business proposition no state can make a better investment, or one actually paying larger dividends, than to insure that the feeble-minded women of child-bearing age are prevented from bringing defective paupers into the world to go on reproducing themselves in geometrical ratio. The direct money saving from this result alone in a few generations would represent a sum equal to the cost of maintenance of the entire feeble-minded population of the state. The much quoted history of the Jukes family showed that in seventy-five years the community paid over one and one-quarter millions of dollars for caring for the paupers and prosecuting the criminals who were the direct descendants of two feeble-minded sisters" (Fernald, 1904, pp. 384-385).

"If my estimate is within bounds, the entire money cost of removing this dreadful stain from out nation would be, after an expenditure by each state of an average amount of less than half a million for lands and building, a maintenance fund of about ten cents per annum for each of the inhabitants of the United States.

"How foolish is the action of the public in saving such a small amount at the spigot and wasting so profusely at the bung! Ought not this question be made a burning one? Ought not every one convinced of these facts to cry aloud, and spare not, until the legislature of every state shall have the facts burned into their hearts and consciences, as they are now into ours?

"Unfortunately, it is the superintendent of state institutions who are usually compelled to propose the extension of their work. And then they are accused of extravagance, of a desire to glorify themselves at the expense of the taxpayer. The truth is that they are the ones who feel most keenly the needs that they assert; and, if they do not speak, all will be silent" (Johnson, 1896, p. 218). "The cost of segregation will be large, but not so large as the present cost of caring for these same persons, to say nothing of their progeny in future generations" (Fernald, 1915, p. 295).

But some years earlier, in one of the first public statments of indicment, Walk (1890, p. 441) had predicted correctly: "If you are going to shut up all the idiotic and feeble-minded where they can do no harm, you must do it in a cheap way." "If it cannot be done at a cheap rate, you can never get money to do it."

The professionals were caught between their convictions about the absolute necessity to segregate the largest numbers of retardates, and the limitations of legislative appropriations. In desperation, they developed three interrelated plans: (1) by reducing per capita costs, more retardates could be admitted on a given budget; (2) by increasing the population of institutions, per capita costs would come down; (3) by having higher functioning residents work the land and take care of lower functioning residents, costs could be reduced. If these proposals were implemented, perhaps costs could be so reduced that eventually all retardates might be enfolded in the institution. This thinking intensified the trend toward economy discussed earlier as a concomitant of the pity period.

"It is true that the cost of these schools has been great in the past, and when we consider the number to be provided for--at least ten times as many as are now in the institutions--the total cost would appear prohibitory of this plan. But just as soon as it is demonstrated that a large proportion is self-supporting; that the improvables can be cared for, with decency and humanity, at a very moderate ratio of expense, by utilizing the labor of the trained higher grades; that only the younger ones, who belong to the educable grade, and a few of the lowest grade violent and dangerous idiots, require a high per capita cost--it seems probable that the means to gather in and care for the whole class will be forthcoming. When that period arrives, the number of idiots and imbeciles in the nation will cease to increase, and, if other classes of degenerates can also be brought under control , the number my diminish very rapidly" (Johnson, 1898, p. 471).

An argument that became very popular was that since most community breadwinners must support three or more persons, a retarded resident who was one-third as productive as a community worker would be self-supporting. "When the feeble-minded are recognized in childhood and trained properly, many of them are capable of being supported at low cost under institution supervision" (Fernald, 1915, p. 295). At least for a while, apparently everyone believed that self-sufficiency and complete segregation of retardates was to be found in the work potential of the residents. "The only hope that I can see of the state taking complete care and responsibility of all idiots and imbeciles is that all those who have been trained, those of the higher grade who are susceptible to training, who have been trained to the highest degree possible for them, shall be so usefully employed that they may be practically self-supporting. We need a great deal of low grade labor, and a great deal of labor can be performed by laborers of a low degree of intelligence. In the care of the lowest custodial grade of imbeciles, in the care of epileptics of low grade, there is a great deal of labor available among our trained imbeciles; and they can do no better work than to exercise such care in an institution" (Johnson, 1902, p. 492).

Beginning in about 1880, so-called farm colonies had come into vogue. In essence, they were institutions that specialized in making higher functioning retardates as self-supporting as possible by having them farm large tracts of land. Knight (1891), Fernald(1902), Mastin (1916), and Bernstein (1918, 1920) presented key models of such facilities. The belief developed that with enough land, an institution could actually become self-supporting. The rule of thumb that appeared to materialize out of nowhere (e.g., Osborne, 1891) was: one acre per resident. "Having decided upon the number of inmates, at least one acre of land for each inmate should be purchased" (Fish, 1892, p. 163). "It has been conceded for years that each institution should be provided with at least one acre per inmate; and, as we grow in years, it is thought by some that even more than this is needed" (Powell, 1897, p. 295). "The colony estate should be large, fully an acre to each individual. It is far better to have a little too much land than too little. We have at Sonyea 1895 acres, on which it is proposed ultimately to place 1800 people" (Sprattling, 1903, p. 261). "The site for an institution should comprise 1 acre of land for every pupil when the institution has reached its maximum" (Wallace, 1924, p. 258).

With such a rule of thumb, institutions soon became monstrous in extent: "The colony farm for the adult feeble-minded of Massachusetts is one of the largest of its kind in the world, covering several square miles of land" (Johnson, 1903, p. 250). "The Craig Colony estate (In New York), three miles long and a mile and half wide, ..." (Sprattling, 1903, p. 261). Powell (1897) provided detailed information on U.S. institutions, including number of residents and land holdings. If one computes the average acreage per resident, one arrives at a figure of 1.01. By 1915, Bureau of the Census (1919) data indicate that average per resident acreage had risen to 2.47 or 2.99, depending on how the average is computed. By 1922, the heyday (hay-day?) of farm colonies seemed to be past, as average acreage was down to 1.31, and by 1933, it had fallen further to .62 (Bureau of the Census, 1926, 1935).

Doren had been superintendent in Ohio for many years, and in 1884, he reported that 24-30 percent of his residents "become capable of self-support" (Kerlin, 1884, p. 251). In the mid-1880's, Doren made a fateful boast: "The superintendent of the Ohio institution has made a proposition to the legislature of that state like this: Give me the land and allow me to gather the idiotic and imbecile population now under public care together, and I agree that the institution shall be made self-sustaining, and I will pay back to the state the price of the land" (Byers, 1890, p. 441). As widely quoted and repeated, (e.g., Kerlin, 1886; Knight, 1891, 1892; Fernald, 1893., Follett, 1895; Bicknell, 1896; Byers 1916), Doren was said to have stated that 1,000 acres would suffice to carry out his claim.

"I am quite sure that with sufficient farm land, and in connection with our present institution, the adult able-bodied imbeciles of both sexes could be kept in our state at a weekly cost of not more than $1 per capita in addition to what the farm would produce" (Johnson, 1896, p. 218). By 1902, Johnson (p. 492) stated that the average annual maintenance cost in an Indiana farm colony was actually down to $32, which must have referred to a very select subgroup, as overall maintenance costs in Indiana were about $136 in 1902.

Residents were worked to the limit of their capacity, and, it appears, sometimes even beyond: "They should be under such conditions that many of them shall not cost the tax-payer anything...the state must...say to them "We will take care of you: you shall be happy and well cared for and clean and useful; but you shall labor and earn your bread in the sweat of your face according to the divine command.' That is what ought to be done with the whole class of degenerates, just so far as it is possible to do it" (Johnson, 1901, p. 411). Mastin (1916, pp. 34-35) declared that what was "...heart-breaking and unprofitable work for normal persons..." would be "...'particularly fitted'..." and "...agreeable, if not joyful occupation..." for retardates. "...You cannot work those boys too hard. If they work them as hard as they can they will not practice the vices...." "Let them go out and work just as hard as they will work. That is what they have to do for me when they work on the farm. They work so that when they come in at night they go to bed and sleep. Then they get up the next morning and go to work again, and I am very sure that the farmers who are working them the hardest are keeping them the best in line of good behavior. Miss Boehne suggests that the boy was overworked. Of course, we know that there are some tubercular conditions among the feeble-minded, that should be considered. About half of our population are subject to these same conditions" (Bernstein, in Fernald, 1915, p. 105).7/

7/For a long time, tuberculosis and related diseases appear to have been the leading cause of death in institutions for the retarded (e.g., Barr, 1904; Butler, 1944; Kaplan, 1939; Martz, 1934; Richards, 1954; Theodos, 1948). The implications of this fact do not seem to have been adequately elaborated in the literature of the field.

Residents might not only be worked like animals, it seemed, but also received about as much (or even less) medical care: Mastin (1916a, 1916b) and Swan (1908) boasted that medical expenses for over a year in one of the Massachusetts farm colonies was a total of less than one dollar for all 50 resident males combined. This stands quite in contrast to Fernald's earlier (1902, p. 489) description of a farm colony, prior to the cost squeeze: "They trap woodchucks, pick berries, gather nuts. They have their baseball nines and their football teams. They go coasting and skating in the winter and swimming in the brook in the summer. What more can a boy want?" (Fernald, 1902, p. 489).

There was much self-delusion and falsification of facts regarding maintenance costs, and I found it difficult to distinquish between claims as to: how many residents were discharged as self-supporting; how many were considered potentially self-supporting in the community; what the maintenance costs were; and what the maintenance costs might have been. "Dr. Walter E. Fernald, of Massachusetts, in speaking on this subject, says: 'Not over 10 or 15 percent of our inmates can be made self-supporting, in the sense of going out into the community and securing and retaining a situation, and prudently spending their earnings. With all our training we cannot give our pupils that indispensable something known as good, plain common sense" (Carson, 1898, p. 295). The superintendent of Lapeer, Michigan, claimed: "Twenty-five percent of our inmates would be self-supporting if the work were put into their hands to do" (Polglase, 1900, p. 425). "Mr. Alex. Johnson says that in his institution 50 percent of his inmates are self-supporting" (Fox, 1900, p. 431).

"The proportion of the feeble-minded who may be made to earn their own living, under control, is variously estimated. The superintendents of at least two of the large training schools, both men of practical common sense, place the estimate as high as 50 percent of the whole number admitted. It is instructive to notice that estimates of this kind tend to become larger, especially as made by the managers of institutions which have a large acreage of farming and fruit-growing lands" (Johnson, 1898, p. 469).

"The cost of maintenance for mixed classes of patients in colonies after the population reaches 600 to 700 will be less than for the insane; while colonies for selected cases only should not require more than $75.00 to $80.00 a patient a year, and under ideal conditions even less" (Sprattling, 1903, p. 267).

"Build them up as high as you can, keep them where they are safe and will be industrious, and half of them, perhaps more than that, may be entirely self-supporting and no burden upon the tax-payer at all" (Johnson, 1905, p. 537). While records show that maintenance costs in Pennsylvania were about $175 a year, superintendent Kerlin was quoted as follows: "Dr. Kerlin tells me that, when they had three hundred inmates, it cost them twenty thousand dollars for expenses.

Now, with seven hundred inmates, it does not cost any more. What does that mean? It means that the feeble-minded themselves are doing the work and helping to solve their own problems" (Barrows, 1888, p. 400). Even though Kerlin was probably misquoted, it is of significance that prominent workers in the field were ready to believe that costs were down to $29 per year. Fernald can be seen to be stretching the truth a bit in the following statement: "The average running expenses of these institutions have been gradually and largely reduced by this utilization of the industrial abilities of the trained inmates. At the Pennsylvania institutions the per capita cost of all the inmates has been reduced from $300 to a little over $100 per annum..." (1893, p. 218). The records showed Pennsylvania costs to vary from 152 to 175 between 1889 and 1894. Johnson (1900) and Bernstein (1918b) gave boastful papers on "self-sustaining" retardates even as the maintenance costs at Bernstein's institution (Rome, N.Y.) were $150 a year. A breakdown of the 1928 average maintenance costs of 24 farm colonies for males at Rome State School showed a range of $186-508, with a mean of $260 and a median of $232 (Davies, 1930, p. 225).

While retardates' work and development of farm colonies did not make the institutions self-sufficient, costs were, indeed, reduced, held constant, or held down to an astonishing degree. "Many years of experience have taught us economy of administration; and, while the efficiency of service is constantly increased, the cost of maintenance is gradually diminished. It will be found, after making due allowance for the number cared for and the difference in cost of supplies at various points, that the average per capita cost is remarkably uniform" (Wilmarth, 1902, p. 153).

Superintendents vied with each other in reducing cost, and aside from farming, another way to economize was to develop institutional architecture that was "plain but substantial": "The buildings themselves should be exceedingly plain and simple. What instrinsic reason is there for building more expensive structures than middle-class people build for their own dwellings in the same community?" (Fernald, 1902, p. 490). "Plain, substantial buildings, with modern sanitary toilet facilities, and of architectural beauty, but no filagrees, are what we need" (Johnstone, 1908, p. 323). "...Permanence in construction with low maintenance cost..." (Kirkbride, 1916, p.255). "The institution that we provide for the feeble minded should be constructed and maintained at a moderate cost. There has been a disposition to build marble palaces for the most degenerate members of the community..." (Cornell, 1915, p. 334).

In 1893, Fernald (p. 220) stated that capital expenditures per bed should be no more than $400. By 1916, Byers (p. 227) asserted flatly: "The state that expends more than $300.00 per bed for the buildings and equipment of a colony from one to three hundred inmates, spends too much."

Stripping the retardate's environment of amenities and comforts so as to cut costs was accompanied by tortuous rationalizations: "As a rule, mental defectives are descended from the poorer classes, and for generations their people have lived in homes having few conveniences. To expect them to be content in a great city institution with its up-to-date furnishings and equipment, and its strict routine, is unreasonable. They find little comfort in steam heat and polished floors; and the glare of electric lights too often adds to their restlessness. It is useless to hope that they will ever be happy as it is possible for them to be if we do not gratify their love for open spaces or provide for them the opportunity to live the simple out-of-door life under circumstances which will enable them not only to keep busy but to enjoy the fruits of their labor" (Mastin, 1916, p. 245). A statement uncomfortably close to suggesting warehousing of retardates was attributed to Fernald by Kirkbride (1916, p. 253): "It is obvious that if large numbers of the feeble-minded are to be cared for the cost of housing them must be reduced to a point where it cannot be criticize by the business man and the tax-payer." "The ornamental or decorative features of the old-time institution will have to go, if this is to be accomplished." "We have only begun to utilize the beautiful, well-proportioned commerical type of buildings, such as the General Electric Co., the Bridgeport Arms Co., etc. are building."

In the early days, costs at Elwyn in Pennsylvania had been $350; by about 1890, they were down to about $175 (Kerlin, 1890), and to $152 in 1893 (see Appendix 1). Wilbur estimated that average maintenance costs were about $200 in 1888 (p. 108). Powell (1897, p. 296) thought that cost could be reduced to about $150 or even $125. Almost in desperation, Cornell (1915, p. 334) exclaimed: "Until we get the per capita cost of the high grade feeble-minded down less than $100 per year there will be objection to their segregation on the ground of expense."

Although attempts to become self-supporting failed, the relative true expenditures hit a low during the indictment period, not to be equalled even during the depth of the depression (see Appendix 1). As costs went down (at least in relation to the value of the dollar), admissions went up. Successively larger institutions were rationalized as being of ideal size, and as size grew, the rationalizers moved on from one rationale to the next. "One thousand inmates should, in my opinion, be the maximum number under one management" (Fish, 1892, p. 163). Knowing what was to come, we shudder as a small voice of caution is brushed aside: "Mr. Garret has referred to the fact that, in the establishment of an institution for a thousand of the feeble-minded, the identity of the individual child may be lost sight of. I think there is possibly some ground for that fear; but in our institution, which is planned to care for a thousand eventually, we do not find any lack of the same personal care and interest on the part of caretakers and attendants. Their enthusiasm and interest are just as great as in the beginning of the work. I do not anticipate any evil results in extension of the work on the line suggested" (Fish, 1892, p. 349).

H.M. Green (1884) and Wilmarth (1900) suggested that institutions not exceed 1,000. Murdoch (1909) expressed the hope that his institution would remain at 1,340, but by 1913 he had capitulated, calling for 2,000-3,000. R. A. Green (1927) called an institution for 1,000-1,500 "ideal." Sprattling (1903, p. 261) was planning an institution for 1,800. Hart (1896, p. 488) of Minnesota said: "Our buildings are excellent; but they sadly need enlargement. We could have, I think, 2,000. The demand is convincing and unanswerable." "I do not believe that the size of an institution should be so limited. It seems to me that two or three thousand can be cared for in one institution when the possibilities of grading and grouping are so great. Why should we not have towns of them? If the superintendent is an organizer, it is a benefit to the state to take care of three thousand in one institution. I would not put any limit to the number that a man can properly handle" (Smith, 1913, pp. 39-40). Finally, the cork was pulled together: Polk (Pa.), which had been built to relieve crowding at Elwyn, and which had had 1,200 residents in 1906 (Murdoch, 1906), had grown to 2,300 residents, 84 percent overcrowding, and a waiting list of 500 by 1928 (Watkins, 1928); Columbus (Ohio) had 2,430, with construction underway for 240 more, and funds appropriated for yet another 700. Superintendent Emerick threw up his hands; much like Fernald (1893), he said, in his presidential address to what is now the American Association on Mental Deficiency: "It seems easier to get the legislature to appropriate funds for more buildings, for the institutions we already have, than it does to get new institutions, but as the institution at Columbus is now so large that the Superintendent cannot keep in touch with the inmates, it might just as well have a population of 10,000 as 3,000" (Emerich, 1917b, p. 74; see also Emerick, 1917a).

A peculiar but commonly repeated twist of logic in support of enlargement was advanced as early as 1895: "Each year the number committed to our care has been a considerable increase over that of the preceding; and we have now reached a population at which our extended accommodations are exhausted, with numerous applicants knocking at our doors for admission. Provisions to meet this demand are already near completion. This numerical statement is a most gratifying proof of the good work of the institution, and positive evidence of the full confidence of all public-minded, charitable citizens" (Winspear, 1895, p. 163).[8]

The menace image of the retardate, and the perceived necessity to farm large tracts of land for large groups of residents, combined to result in the locating or relocating of most institutions away from population centers and in rural areas where farm land could be had inexpensively. This exacerbated the trend toward isolation begun during the pity period: "Massachusetts has purchased for its school for feeble-minded at Waverley, 2,000 acres of cheap land, sixty-one miles from the parent institution and has already established on it three colony groups of about 50 boys each, the two extreme groups separated by two miles. These boys live amidst simple, plain environments and in almost primitive, yet comfortable style. Dr. Fernald is there making a practical demonstration of the possibility of carrying out the plan above indicated, in a manner both economical to the state and conducive to the best interests and happiness of the boys themselves. The plan is economical because of the simplicity of the equipment required. There is no necessity here for expensive buildings, like schools or hospitals, with their necessary apparatus" (Rogers, 1903, p. 257).

In 1913, Murdoch (p.36) called for institutions of 2,000-3,000 located "...far from any large city and rather isolated..." and on 3,000-4,000 acres of land. By 1930, isolation had become so accepted and real that he reversed himself slightly, advocating, in all seriousness, that institutions "...should not be too isolated, and should be near enough to a village where employees may do their shopping, find social interest, and entertainment" (p. 243).

For a long time, Johnstone (brother-in-law of A. Johnson) and Kirkbride where the only ones to raise a voice in partial opposition to the prevailing thinking. For several years, the myth was maintained that farm colonies would eventually attain self-sufficiency, and considerable discrepancies are apparent between euphoric public claims and actual cost figures. This led Johnstone (1906, p. 239) to observe: "The farm colony idea with a reasonable number of paid employes and a large extent of farm land, has made many institutions much nearer self-support, but still the per capita cost is over one hundred dollars per annum. Many of us have hitched our wagons to this star, but the millenium cometh not yet" (Johnstone, 1906, p. 239). He also objected to the continuing enlargement of institutions (e.g., 1908, 1913) and argued for some semblance of humanizing treatment of retardates generally: "I have not gotten beyond the five or six hundred mark as yet. From an economical standpoint, I believe about 750 would be the most desirable size. I have argued against a large number being placed in one institution for that reason. If the institution is not very large, we get good classes. When we put men in one institution, women in another, and children in another, are we not taking away entirely the family idea?" (1913, p. 40).

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[8] It should be noted here that the growth of institutional places far exceeded the growth of the population. In 1904, there were 17.5 places per 100,000 population; in 1910, it had grown to 22.5; in 1923, it was 39.3; and by 1956, it had reached 66.1 (Davies, 1959). In 1966, it was 98.7. Furthermore, it should be noted that each bed during the indictment period could serve a much larger number of residents than today, because the turnover rate due to deaths was very high.

Johnstone can be seen as "least extreme," but as far as opposition to the principle of segregation was concerned, there was none from the professional ranks: "We must beware of assuming universal consent because no serious note of opposition has been heard" (Johnson, 1903, p. 245). Personally, I found it both instructive and depressing that between about 1890 and 1918, I found not a single speaker or writer in opposition to the prevailing views of the retardate as a sinister menace. It made me wonder what nonexisting voice future reviewers will seek for our own epoch.

Failure to Support Community Alternatives to Segregation.

The workers in the field painted themselves into a corner by advocating a practically unfeasible, scientifically invalid, and sociopolitically unacceptable policy of segregation while systematically rejecting alternative provisions such as education and family support.

During the alarmist period, education was no longer seen as effective in diminishing the degree of a person's retardation, and was not believed to prevent a retardate's depravity: "When the state has taken the imbecile, and by training has brought out the best there is in him, when it has corrected his faults, so far as education can do it, when it has possibly taught him to read and write, to be more engaging in his manners and more attractive in appearance and bearing, and then has discharged him with his inherent defects in no way removed, to marry and perpetuate his kind, has it really done a commendable deed?" (Wilmarth, 1902, p. 159).

Thus, education came to be viewed as worthless. Rogers (1898), superintendent of Faribault (Minn.), questioned: "Does the Education of the Feeble-minded Pay?, and Johnson (1899, pp.228-229) stated:

"We made a mistake in keeping many children in school too long and taking them farther than they will have any need for." Bernstein (1913, p. 59) observed: "The patients who give us the most trouble are the ones who have been taught to read and write. They are always looking for an opportunity to send out a letter or note secretly, and give us trouble in other ways as well. If they could not write, much of the disturbance would be eliminated."

Even special education in the community, far from being seen primarily as a constructive and viable alternative, was seized upon as a means of identifying retardates for subsequent institutionalization: "If...the special schools were so conducted as to constitute clearing houses to separate the inherently feeble-minded from those whose mental growth is retarded by circumstances temporary in character, they would serve a useful purpose; but if they are attempting the impossible, the education of the inherently feeble-minded to equip them to battle single-handed in the struggle for existence and thus prevent their entrance into institutions during their early years, they are harmful. It is our duty to point out the limitation of usefulness for such schools" (Murdoch, 1903, p. 71; similarly, 1909, pp. 65-66; Fitts, 1915; and Schlapp, 1915, p. 325). "The modern public school class for defective children ensures diagnosis and treatment at an early age, helps to inform the parents as to the dangers of mental defect, and admirably serves as a clearing house for permanent segregation, when necessary before adult life is reached. These classes should be established in every city and large town" (Fernald, 1915, p. 293).

Another community alternative that today strikes us as most progressive, viz., the granting of a subsidy or "pension" to needy families with retarded persons in the household, was viciously attacked. Kentucky had had such a law since 1793 (Estabrook, 1928; Fernald, 1893), but superintendent Stewart from Kentucky (1894, p. 311) confessed that he was "...ashamed to tell you of our idiot law," and said that he had tried for 16 years to have the law repealed. He likened this law to the scalp law for foxes under which every fox scalp was rewarded with a $2.50 bounty until people took to raising foxes. "Now there is a premium offered for idiots." "The system is heinous" (Reports from States, 1890, p. 322). Dunlap (1899) also expressed disapproval of the pension law, and Estabrook (1928) suggested that it be repealed and the money used to enlarge the institution instead!

Finally, even the newly developing psychological community clinics were interpreted as agencies of the eugenic work (e.g., see Journal of Psycho-Asthenics, 1913, 18, 13) rather than of community assistance.

The End Of The Indictment

The peak of the indictment period was between about 1908 and 1912. By about 1920, workers in the field began to recognize two facts. Firstly, studies of the community adjustment of retardates showed that they were not the menace as had been thought; and secondly, it was realized that the aims of segregation could not be achieved. One of the first major admissions of the failure of both sterilization and segregation took place in an address by Taft (1918), who commented: "...when by segregation we mean a fairly complete shutting off from society of all the feeble-minded, including the higher grade types, we ignore a profound aversion on the part of people in general to confinement for life for any human being, particularly when no offense has been committed commensurate with such punishment and when the individual to be segregated seems to the ordinary observer not to be very different from himself. This, combined with the feeling which relatives, particularly of the high grade feeble-minded have against segregation, makes any very complete program of this kind quite impossible for some time to come" (p. 545).

As early as 1915, Fernald (p. 296) had observed that "the courts are seldom willing to utilize even existing commitment laws without the consent of the parents, except in extreme cases." Perhaps the only justification for naming Howe's original institution for the Great Indictor himself is that Fernald, in the past years of his life, reversed himself, first in a celebrated speech in 1917. In 1919, he said: "The average citizen is not yet convinced that he should be taxed to permanently support an individual who is capable of thirty, fifty or seventy percent of normal economic efficiency, on the mere theory that he is more likely than a normal individual to become a social problem" (pp. 119-120; see also Fernald, 1924). "In practice it has been found very difficult to ensure life-long segregation of the average moron. The courts are as ready to release the defective as they are to commit him in the first place. However proper and desirable it may be in theory to ensure the life-long segregation of large numbers of the moron class, it is a fact that there is a deep-seated prejudice on the part of lawyers, judges, and legislators towards assuming in advance that every moron will necessarily and certainly misbehave to an extent that he should be deprived of his liberty. That such misgivings are well-founded is apparently shown by the studies made of discharged patients at Rome and Waverly. At Waverly, a careful study of the discharges for twenty-five years showed that a very small proportion of the discharged male morons had committed crimes, or had married or become parents, or had failed to support themselves, or had become bad citizens." "We have begun to recognize the fact that there are good morons and bad morons, ..."(pp.119-120). After hearing Fernald in 1917, Murdoch (1917, p. 41) said: "...the pendulum ...had gone too far and is coming back."

"It is a matter of history that the two principal measures of social control in which main reliance was placed, during this period of alarm, for coping with the problem of mental deficiency, namely, sterilization and segregation, have failed to meet the situation as completely as the proponents of these measures had expected" (Davies, 1930, p. 130).

Taft (1918) proposed a new alternative to the field: identification, supervision, and control of the retardate in the community. This, it was widely felt, required that all retardates be registered (Hasting, 1918), and there was widespread agitation to accomplish this. Fernald had advocated such registries all his life (for partially different reasons), but now the idea found new support, although to no avail.

The 1930 White House conference on Child Health and Protection proposed a three-stage program to attack the problem of retardation. Stage one was identification and registration; stage two was divided into training of some and segregation of others; and stage three involved supervision, or, as it was frequently referred to, "social control," of the community retardate. Registration was the key to the entire program. A most prominent text of the period between the alarmist one and the new enlightenment of the 1950's was Social Control of the Mentally Deficient (Davies, 1923, 1930).

Today, of course, we know that most retarded adults make an adequate adjustment in the community, and that they are more likely to be the victims rather than the perpetrators of social injustice. It is also widely accepted that heredity is a relatively insignificant factor in the causation of retardation, as compared to maternal health and socio-cultural factors.

Momentum Without Rationales

We are now coming to a crucial point in this exposition. We cannot understand the institution, as we know it, with all its objectionable features, unless we realize whence it came. I propose that essentially, many of our institutions, to this very day, operate in the spirit of 1925 when inexpensive segregation of a scarcely human retardate was seen as the only feasible alternative to combat a social menace. I am not proposing that this view is still held; I am proposing that most institutions function as *if this* view were still held. I will try to explain this hypothesis.

From 1847 to about 1925, institutions had evolved dynamically as ideas and innovations followed each other continuously. We can now judge the ideas faulty and the innovations as ineffective in achieving goals, but the force and dynamism of the institutional development cannot be denied. By 1925, however, a curious situation had developed. Essentially, the large institution, built for the ages, remote from population and teaching centers, was bereft of rationales. The only major rationale left was relief for hard-pressed families of the retarded, and if this rationale had been taken seriously it would have called either for community services, and/or for specialized and dispersed residential centers of a more humanizing character, and nearer to population centers. Furthermore, the institutions were so crowded that it might have taken a decade without any admissions at all to reduce residents to an appropriate number.

If the field had continued to evolve as logically as it had until about 1925, it is clear that community and special residential services would have been developed and institutions of the type we still have with us today would have withered away. However, community services did not develop fast enough, and this is probably one of the major reasons institutions did not change. Why these community services failed to develop is not simple to answer. I propose that four reasons may be paramount:

1. The professionals had indoctrinated the populace for about 30 years regarding the menace of retardation, and were to continue to assert the unchangeability of intelligence for another 30 years; thus, probably only a prolonged campaign of attitude modification (as finally developed in about 1950) could have secured community services.

2. Partially because of the pessimism communicated by the workers in the field, the interest of professionals became attracted to the new discoveries and increasing treatment opportunities in the area of mental health. A change in orientation of the National Conference on Charities and Correction reflected and/or contributed toward this trend. One of the organizers of this body in 1874 had been H. B. Wilbur, a pioneer in mental retardation. For almost a half century, the Conference was one of the major meeting grounds between professionals in the field of mental retardation and other professionals and public officials. In 1917, the name was changed to the National Conference of Social Work; it became more of an association for one particular profession rather than a meeting ground and forum for many; and as papers on mental health and hygiene increased in frequency, papers on mental retardation began to diminish and eventually disappear.

3. The depression stifled progress in the development of social services other than those considered essential to economic survival of the nation, and mental retardation services are generally given low priority even when times are good.

4. World War II further diverted popular attention and concern. It is noteworthy that the "new look" in retardation began in about 1950 when there was prosperity and when war-related problems, such as demobilization, reintegration of veterans, and housing shortages, were finally being solved.

Any "institution" (in the sociological sense) that has much momentum but no viable rationale is likely to strive for self-perpetuation on the basis of its previous rationales and practices. And this is what I believe to have happened to our institutions (in the conventional sense). But 40 years of not thinking about our institutional models, and of model muddle (Wilkins, 1965), is enough! Let us consider only the following aspects that the institutional movement of today shares with the past, although these aspects no longer have viable rationales:

1. Large older institutions being further enlarged.

2. New institutions designed to be large, i.e., for more than 600-1,000 residents.

3. New institutions placed in inconvenient or remote locations.

4. Perpetuation of the omnibus (rather than specialization) concept of institutional purpose.

5. Uncritical and poorly rationalized intake practices; for instance, one need consider only the large number of young mongoloids from adequate families that are accepted, often in infancy or from birth.

6. Continuation of dehumanization, despite the unprecedented move throughout the country toward increase in personal rights, equal protection under the law, distribution of affluence, better opportunities for the disadvantaged, etc. We see this concern expressed in civil rights laws, controversy over draft laws and the Vietnam war, definition of students' rights, reformulation of the rights of the accused, and the revision of the codes of ethics of many major professional societies. We are only beginning to see this concern extended to the retarded.

The Realities of Institutional Accomplishments

If we compare the rationales for institution building with the realities of institution accomplishments, we can see that few of the hoped-for aims have even been approximated; that none of the major rationales advanced for institution building and institution running has held up; and that virtually every novel concept in institutional care was perverted eventually.

1. The schools became asylums, and small family residences became large regimented institutions. Most retardates placed in these institutions were not made nondeviant; to the contrary: placement more often resulted in systematic "dehabilitation" (Sharman, 1966) which accentuated deviancy. This was only to be expected since any agency designed for the keeping of large numbers of deviants can ill afford to tolerate non-deviance in its midst, as illustrated by an experience of Fernald's: "I would like to ask the members of the Association what experience they have had in paying imbecile help. We have not done that very much, except in one or two cases. We had a very good driver who had been with us a few years; some suggested that we pay him ten cents a week; in the course of a month or two he thought he should have twenty-five cents, and so on to exorbitant ideas of his value, and such stretches of discipline and disobedience, that the only way to get him back to his tracks again was to put him back in the ranks" (Fernald in the discussion of Osborne, 1891, p. 181). "...*The social integration of the subnormal...is never feasible if society does not permit the subnormal to reach this integration*" (Speyer, 1963, p. 162), and the institution did "...not provide an accurate model of the society to which some of the retarded will eventually need to adjust" (Kirkland, 1967, p. 5).

2. The institution became not a paradise but a purgatory, not a Garden of Eden but an agency of dehumanization; to this day, residents are subjected to physical and mental abuse, to neglect and inadequate care and services, to environmental deprivation, and to restriction of the most basic rights and dignities of a citizen.

In 1886, Kerlin (p. 294) had a vision of what was to become the institution at Faribault, Minnesota: "...we turn most approvingly to Minnesota's noble offering for this charity. Located on the beautiful bluff on Straight River, Faribault, with a singularly attractive country adjacent, exciting the kindliest interest of an intelligent and warm-hearted community, and with every advantage of space, fertility of soil, and amplitude of water, we know of no institution in the United States so happily and wisely begun. In fact, like the noble state itself, this institution is only embarrassed by the richness of its opportunities." And how does Faribault of today compare with this earlier vision of it?

Sonoma State Hospital in California was born in a similar vision: "The tract of land selected lies in the beautiful valley of Sonoma. It...embraces over 1,600 acres. It is watered by three living streams, two of which rise on the place and give us 100,000 gallons of water daily, at an elevation of 150 feet above the building site. There are over 50,000 fruit-trees on the place, besides acres of vines and hundreds of acres of pasturage. Two railroads pass through the land, and will give us stations on it. The climate is perfect, the situation picturesque, the location central; and, altogether, the trustees are jubilant, and feel that the millennium is at hand. There seems no reason why our Home should not be the equal of any institution in the land. We shall not be satisfied with any lesser glory" (Murdock, 1889, p. 316).

"In mountain heights, past stream and plain,
And by the redwoods forests' sweep.
In this broad land a spot is found,
Aye! call it ever hallowed ground." (Osborne, 1891, p. 175)

Could anyone believe that this hallowed Garden of Eden became the institution for 3,400 and one in which, according to a recent prominent visitor from abroad, residents are treated worse than in any institution he had seen in a dozen countries and, indeed, worse than cattle are permitted to be treated in Denmark (Children Limited, Dec. 1967, p. 2). Or that a mother recently preferred that her child die than live at Sonoma? (Anonymous, 1968).

In 1901, an observer remarked that retardates in a certain Midwestern institution were being herded like so many cattle (Clark, 1901). Today, 68 years later, the residents are still being herded like cattle in the same institution in that cattle-oriented state. How many more years?

A 1787 visitor to Pennsylvania Hospital, the first U.S. public institution to receive the mentally afflicted for treatment, saw naked residents bedded on straw, in locked, underground, dungeonlike cells that had small windows for passing food, and he exclaimed in seeming self-satisfaction that "...every possible relief is afforded them in the power of man, " rejoicing in "...the pleasing evidence of what humanity and benevolence can do...." (Deutsch, 1949, p. 62). Deutsch also described a case cited by Dorothea Dix in 1847, in which a harmless deranged person was kept summer and winter in a open pen. He was fed hog slop and kept on straw which was changed every two weeks in summer, less often in winter. He was exposed to rain, heat, cold, and snow, and his feet had frozen off into shapeless stumps. The keepers of this wretch, however, saw themselves as offering kind treatment.

Today, all of us see the inhumanity of such treatments, because our values have grown. But some of us do not see the 1968 equivalents of the 1787 and 1847 treatments, or of the keepers' responses. Are not, in 1968, denial of property rights, of human contacts and perceptual stimulation; restriction of movement and communication; denial of wages for work; compulsion to use nonprivate toilets; denial of the privilege to wear clothes; behavior control by means of medication rather than education or guidance; enforced idleness; and innumberable other practices common in our institutions the equivalents of the inhumane practices of 1787 and 1847? Are not the rationalizations of these 1968 practices equivalent to the protestations advanced by the keepers of 1787 and 1847? How will the professionals and public of 2068 judge them?

3. Institutional segregation did not contribute much to prevention of retardation, and the deviant retardate is still with us. Indeed, there is reason to believe that with the increasing complexity of life, the number of persons who will fail to meet societal demands will increase.

4. Institutionalization was not accomplished inexpensively, as had been claimed. The concentration of retardates in large institutions has, in most cases, been more costly than provision of community services would have been. Work, first rationalized as constructive occupation, became exploitation as cost cutting became important and, again contrary to claim, only a modest number of retardates became self-sufficient in the institution. Those retardates who did become good workers began to replace institution employees and thus became too valuable to be released; the institution could not have functioned without unpaid captive labor. To save money, the large solid multi-purpose (usually original) building of the institution was permitted to become an overcrowded dungeon; cottages conceived to replace them became large overcrowded buildings, sometimes housing 200 residents and their attendants (Bliss, 1913); the "plain, substantial buildings" designed to reduce expenses became bare, vast mausoleums; and the colonies which were to relieve institutions of their crowdedness, bring about more humane living conditions, and reduce costs became large institutions in their own right.

5. The concentration of skilled expert staff never materialized, one of the main reasons being the partially self-elected isolation of institutions remote from centers of learning and population. To the contrary, institutions have tended to act as sieves, retaining professionals who are deviant themselves, and passing on the others to universities and community programs. The unlicensed physician, often unable to communicate in English, is notorious, as are professionals who are alcoholics, drug addicts, unstable, or health-handicapped. While it may be desirable to find niches for such individuals, it is significant that such persons should have become concentrated in our institutions. Professionals not good enough to work on us or our

normal children were, it seems, good enough to work on our retarded children. Employees, as much as residents, become "institutionalized" (Cleland & Peck, 1967).

To this day, staffing is a dilemma in both rural and urban locations. Recruiting for nonprofessional personnel is usually easier in rural locations unacceptable to many professionals. Professionals are easier to attract into urban locations, but there, nonprofessional turnover may run 50 percent a year, even with relatively good salaries (e.g., Jaslow, Kime and Green, 1966). The very heterogeneity of residents, desired by many workers in the field, has presented a major problem in staffing because so many different skills and types of training are needed to serve a group with a tremendous variety of problems (Jaslow, Kime and Green, 1966).

6. From the beginning, and ever since, the research potential of institutions has been exalted (e.g., Seguin, 1870; Kerlin, 1885; Sprattling, 1903; Johnson, 1904; Schlapp, 1915), and one of the arguments for congregating large numbers of residents had been that this would facilitate research. This potential has never been fulfilled except at a very few institutions at a given time. Even today, with over 150 institutions, less than a half-dozen can be said to be making a well-sustained, active, and significant research contribution to the field.

7. One goal was often achieved by institutions: providing relief to families. But even here we have an element of irony in that family relief could often have been achieved better and cheaper by other measures than institutionalization.

If my formulations and interpretations are correct, we can summarize the trends in United States residential care for the retarded as follows, and as depicted in Figure 1. Attitudes toward retardates paralleled those toward a number of other deviancies. Around 1850, a developmentally oriented residential model attempted to return the deviant to the community. Between 1870 and 1890, this model was replaced with one based on pity which called for protective isolation of the retardate. This period was brief, and was soon succeeded by one emphasizing the menacing nature of deviancy. Certain trends that had originated during the pity period were accentuated, so that retardates were congregated into huge groups, sequestrated from society, segregated from other retardates of the opposite sex, asexualized, and dehumanized in poorly supported, inhumanely run regimented institutions. The puzzling and anachronistic mode of functioning of today's institutions can be understood if we see them as having been maintained by a tremendous amount of momentum but bereft of rationales for about 40 years.

I submit that the problem of residential services cannot be solved by working on a number of specifics at a time, or by calling for simple-minded, low-level measures such as more money. All the money in the world will not change the minds of men. What we need is concepts and models. The current model, the entire system, as Howe called it, is inconsistent with contemporary cultural values and scientific knowledge. We need a model of services that is appropriate to knowledge, resources, and needs of the 1970's and beyond, and that is based on a contemporary perception of the nature and role of the retarded person in our society. Such new and viable ideology, presented in the next sections of this monograph, is gaining wide acceptance. With the acceptance of this new ideology, we are witnessing the agonized death struggle of an institutional model based on a perception of the retardate as a menace and/or subhuman organism.

The greatest irony lies in the fact that the founding fathers foresaw much of what happened, and repudiated the trend institutions were taking within 20 years of their founding. H. B. Wilbur (1879) stated that he had always been in favor of building specialized institutions rather than enlarging existing ones for multiple purposes. In 1886, Howe gave the dedication speech for a new institution for the blind in Batavia, New York. The fact that he virtually repudiated this institution at its very beginning, and as the guest of honor, cannot be overemphasized, as it constituted an act of incredible courage and conviction. Everything he said applies to the institutions for the retarded as well:

"As it is with individuals, so it is with communities; and society moved by pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which it wishes to lessen.

"There are several such already in this country; and unless we take heed there will be many more. Our people have rather a passion for public institutions, and when their attention is attracted to any suffering class, they make haste to organize one for its benefit.

"But instead of first carefully inquiring whether an institution is absolutely necessary, that is, whether there is no more natural and effectual manner of relieving the class; and afterwards, taking care that no vicious principle be incorporated into the establishment; they hastily build a great showy building, and gather within its walls a crowd of persons of like condition or infirmity; and organize a community where everything goes by clock-work and steam. If there be a vicious principle in the organization, as of closely associating persons who ought to live apart, it is forgotten in admiration of contrivances for making steam do what once was done by the good housewife, with her cook and maid; and of the big bright coppers, the garnish walls, and the white floors.

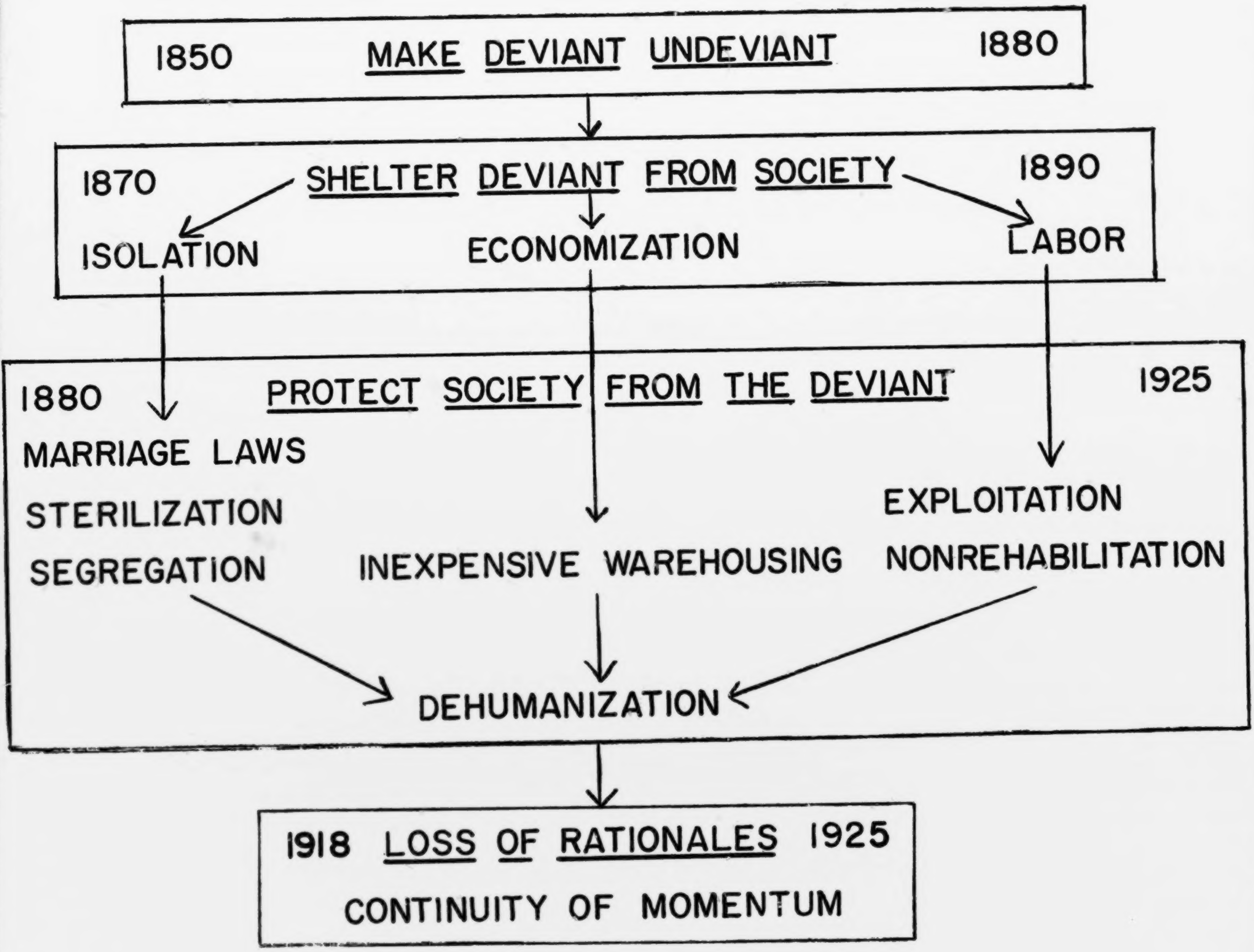
1850
MAKE DEVIANT UNDEVIANT
1880
1870
SHELTER DEVIANT FROM SOCIETY
1890
ISOLATION
ECONOMIZATION
LABOR
1880
PROTECT SOCIETY FROM THE DEVIANT
1925
MARRIAGE LAWS
STERILIZATION
SEGREGATION
INEXPENSIVE WAREHOUSING
EXPLOITATION
NONREHABILITATION
DEHUMANIZATION
1918
LOSS OF RATIONALES
1925
CONTINUITY OF MOMENTUM

Figure 1: Graphic Summarization of the Evolution of Institutional Rationales and Practices

"But no steam power, nor human power can long keep a vicious principle from cropping out. It has done so in many European institutions of charity; it will do so in many of ours" (pp. 18-19).

"...Grave errors were incorporated into the very organic principles of our institutions...which make them already too much like asylums; which threaten to cause real asylums to grow out of them, and to engender other evils. Let me set forth a little my idea of the general principles which should underlie all such establishments, and which have been too much neglected in the organization of many of our public institutions.

"All great establishments in the nature of boarding schools, where the sexes must be separated; where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine, and formality, and restraint, and repression of individuality; where the charms and refining influences of the true family relation cannot be had,--all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as is possible, and those few should be kept as small as possible.

"The human family is the unit of society. The family, as it was ordained by our Great Father, with its ties of kith and kin; with its tender associations of childhood and youth; with its ties of affection and of sympathy; with its fireside, its table, and its domestic altar,--there is the place for the early education of the child. His instruction may be had in school; his heart and character should be developed and moulded at home.

"Artificial families have been tried and found wanting. Communities in imitation of the natural family, especially those confined to one sex, are fertile of evil. Witness the old nunneries and monasteries, darkened and saddened by lack of the sunlight of affection and love; enbittered by petty passions and strife; soured by crushed hopes and yearnings; and defiled by unnatural vices. Witness soldiers in detached garrisons; sailors on long voyages; prisoners under long sentences. Wherever there must be separation of the sexes, isolation from society, absence of true family relation, and monotony of life, there must come evils of various kinds, which no watchfulness can prevent, and physician can cure.

"We should be cautious about establishing such artificial communities, or those approaching them in character, for any children and youth; but more especially should we avoid them for those who have natural infirmity; or any marked peculiarity of mental organization.

"Let me dwell upon this, for in my view, it is very important. Such persons spring up sporadically in the community, and they should be kept diffused among sound and normal persons. Separation, and not congregation, should be the law of their treatment; for out of their infirmity or abnormality there necessarily grow some abnormal and undesirable effects, and unless these be counteracted by education, they disturb the harmonious developments of character. These effects are best counteracted by bringing up the child among ordinary children, and subjecting him to ordinary social and family influences; but, on the contrary, they are intensified by constant and close association with children who are marked by the same infirmity of peculiarty.... We should therefore keep this truth in mind; and give it due weight when forming plans for the treatment of any special class of persons.

"As much as may be, surround insane and excitable persons with sane people, and ordinary influences; vicious children with virtuous people and virtuous influences; blind children with those who see; mute children with those who speak; and the like.

"People run counter to this principle for the sake of economy, and of some other good end, which they suppose cannot be had in any other way; as when they congregate the insane in hospitals, vicious children in reformatories, criminals in prisons, paupers in almshouses, orphans in asylums,blind children and mute children in boarding schools. Hence I begin to consider such establishments as evils which must be borne with, for the time, in order to obviate greater evils. I would take heed, however, against multiplying them unnecessarily. I would keep them as small as I could. I would take the most stringent measurements for guarding against those undesirable effects which lessen their usefulness; and for finally dispensing with as many of them as may be possible.

"But, besides this general objection to such establishments, there is another and more practical objection to the method of congregating...any class of young persons marked by an infirmity like deafness or blindness. They depend more than ordinary persons do for their happiness and for their support upon the ties of kindred, of friendship, and of neighborhood. All these, therefore, ought to be nourished and strengthened during childhood and youth--for it is then, and then only, that they take such deep root as to become strong, and life-lasting.--The home of the blind and of the mute should be his native town or village; there, if possible, he should live during childhood and youth; there he should form his friendships; there, if he comes to need special aid it will be given most readily and fitly; and there his old age will be cherished.--Beware how you needlessly sever any of those ties of family, of friendship, of neighborhood, during the period of their strongest growth, lest you make a homeless man, a wanderer and a stranger. Especially beware how you cause him to neglect forming early relations of affection with those whose sympathy and friendship will be most important to him during life, to wit, those who have all their senses; and how restrict him to such relations with persons subject to an infirmity like his own.

"I would observe, by the way, that the necessity now felt for a new institution in your state has arisen, partly at least, from radical faults in the organization of the old one, which necessarily led to faults in its administration, such as I have noticed. If the conditions of admission had been such as to exclude some who entered, but who ought not to have entered; if stringent measures had been taken to prevent the multiplication of graduates in and about the institution, and to encourage their dispersion and settlement in the several towns, instead of leaving them to congregate in the commerical capital, and to besiege the political capital; if these things had been done, the state would perhaps not now be called upon to incur the cost of building and the continual expense of carrying on a second institution.

"But, it is settled that you are to have one, and, I trust, it will become worthy of the generous motives which prompt its erection; and of the great state which is to build it.

"Take heed that it shall be organized on sound principles; and while copying all the good features of existing institutions, avoid those which are not good. Those establishments are all faulty. Not one of them is worthy to be your model in all respects; and the persons who flatter themselves that their favorite one is worthy to be copied exactly, are blind to faults which can be seen by looking beneath the surface. Never mind their showy buildings and special accommodations; you may as well measure the mortality of a family by the structure and arrangement of its dwellinghouse, as test institutions by their mechanical advantages; but look at the principles and system by which they are conducted. You will, then, find they are faulty in many respects.

"They are generally wrong in receiving pupils too indiscriminately; being, in most cases, tempted to do so by the fact that they are paid according to the number they receive. They are wrong in receiving all pupils as boarders, when they should receive those only who cannot board at home, or in private families. They are wrong in associating the blind too closely, and too many years together; thus loosening or breaking the ties of family and of neighborhood,--segregating them from society,--forming a class apart,--creating a feeling of caste,--and so intensifying all the unfavorable effects growing out of the infirmity of blindness....They are creating the necessity, or the demand, for permanent life asylums; all of which consummations are devoutly to be prayed against.

"Instead, then, of copying the existing institution, I think, that in organizing a new one something like the following rough plan should be adopted:--If the field were all clear, and no buildings provided, there should be built only a building for school-rooms, recitation rooms, music rooms and work shops; and *these should be in or near the centre of a dense population.* For other purposes, ordinary houses would suffice" (Howe, 1866, pp. 39-43).

Howe also repudiated the trend from education to pity: "...aid should not be given in alms, or in any way that savors of alms. Were it possible for government to pension every blind person for life, that would probably do more harm than good. We are safe in saying that as far as possible, they should be considered and treated just as ordinary persons, our equals and friends, are treated, and not singled out as special objects of pity. This is too often forgotten" (Howe, 1866, p. 37).

When I read these passages, I was astonished. Howe had truly "...dipt into the future, far as human eye could see, saw the visions of the world, and all the wonders that would be" (Tennyson). It was as if the founder himself was saying: "Stop it, you fools; we have made a gigantic error!" Alas, Howe had been 100 years ahead of his time, and his cautions went unheeded.

Seguin is probably the best-known figure in mental retardation in this country. He was brought by Howe from France, was instrumental in the founding of about a half-dozen of our early institutions, and was cofounder and first president of what is now the Amercian Association on Mental Deficiency. Yet Seguin (1870), too, disapproved of the trend of things in 1869, and of the developing isolation of the institutions. ". . .In locating these schools through the country..." they have put them out of the reach of concourse of scientific men and means, which are concentrated in capital cities" (p. 43). "This necessity of the situation--for, if these institutions do not progress, they will retrograde--demands of the selection of a suitable place among scientific surroundings; the direction of a man who understands the philosophy of the labor, the selection of microscopists, anatomists, psychologists, young medical men eager for study, devoted women ready to teach, to nurse, and to acquire the capacities so much wanted in other schools. With this force at command, there will be treated, besides the questions directly relating to idiocy and medicine, those which touch society through education. It is not a minute too soon.

"From all the points of the compass, steam and electricity accumulate men and ideas on this continent that will soon be, for good or evil, *the new world*; new for evil if the comers invade us, not by the sword, but their their low spirit of submission to Eastern or Western bonzes; new for good, if we are ready, with a powerful physiological system of education, to assimilate them, women, men, children, of all races and colors, to our unity and independence" (p.44).

In 1878, Seguin added: "...if ideas create architecture, architecture reacts upon its mother-idea, to develop, distort, even kill it (as it appears by the influence that the latter form of the insane asylum has exercised on the theory and practice of the treatment of insanity). Truly, the ideas, too soon cast in brick-form, shrink by compression; and the monument erected for their development becomes too often their empty sarcophagus" (p. 60).

Fifty years ago, Kirkbride (1916, p. 250) lamented, to little avail: "In studying the problems connected with the construction, organization and management of public institutions for defectives, I have had varying emotions....While I have seen much to thrill me and to make me proud of the devoted men and women who are giving their lives to the care of their less fortunate fellows, I have seen so much of the handicaps under which they suffer, resulting from mistakes in planning, construction and arrangement of the institutions in which they work, that my emotions have often been very mixed and sobering.

"Why, I have often asked myself, have the experiences, the failures and the successes of others not been of more use in preventing the needless repetition of costly mistakes? Local customs, politics, prejudice, lack of initiative, courage and vision, and a host of other factors are included in the answer."

The remarkable thing is that our experience has been shared by many countries that built large institutions in the last 100 years. It seems as if the very model, as we have known it, is unworkable.

If it is a universal fact that this model has failed, perhaps the institution built on it is not the solution to our problems. Perhaps the institution as we know it is unworkable and cannot be salvaged no matter how much money we spend.

In Greek mythology we encounter a somewhat overly friendly character by the name of Procustes. He wanted very much to be a good host to weary wayfarers, and when a traveler journeyed past his dwelling, Procrustes would insist that he stay the night with him. After some wining and dining, Procrustes would show his guest to his bed. Trouble was, there was only one bed, of one certain size, and Procrustes was a perfectionist. The bed just had to fit the guest. So if the guest was tall, Procrustes chopped off his legs until guest and bed were exactly of the same size. If the guest was too small, the host strapped him into a rack and lengtened him out a few inches. Obviously, by doing things his own way, Procrustes was prepared for all comers.

The moral of the parable: our institutions have been Procrustean. It did not matter who or what the retardate was, whether young or old; whether borderline or profoundly retarded; whether physically handicapped or physically sound; whether deaf or blind; whether rural or urban; whether from the local town or from 500 miles away; whether well-behaved or ill-behaved. We took them all, by the thousands, 5,000 and 6,000 in some institutions. We had all the answers in one place, using the same facilities, the same personnel, the same attitudes, and largely the same treatment.

And if our guest did not fit, we made him fit!

What we need to do is take an entirely fresh look at the needs of the retarded, and increase the goodness of fit between their needs and our programs. And we must face the possibility that we may need a new bed.

APPENDIX 1

Maintenance Costs of Residents in United States Public Institutions for the Mentally Retarded 1848-1966

Beginning in the section on "Protecting the Deviant From the Non-deviant," and elaborated in the section on "Failure of Preventive Segregation," certain hypotheses were elaborated regarding the relationship between institutional admission trends and institutional costs. To substantiate these hypotheses, I collated data on per capita maintenance costs of U.S. public institutions (or private institutions with a substantial proportion of publicly support residents) for the mentally retarded between 1848 and 1966. In compiling these data, only operating expenses were listed. Where it was impossible to separate capital expenditures and operating expenses, no entry was made.

The data were derived from articles and "reports from states" in the annual proceedings of the National Conference on Charities and Correction and its successor publication, from articles and reports in the various forerunners of the *American Journal on Mental Deficiency*, and from U.S. census and National Institute of Mental Health reports on institutions. In the U.S. censuses of 1850-1890, questions were asked aimed at the identification of retarded persons in the community. In 1880 and 1890, the Census Bureau reported data on residents in institutions for the retarded. Similar resident counts were published in 1906 and 1914, for the years 1903-1905 and 1909-1910 respectively. In 1919 reports on maintenance costs for the year 1915 were added to basic resident movement data. Similar data were published in 1926, 1931, 1932, 1934, 1935, 1936, 1937, 1938, 1939, 1941, 1943,and 1943 again, for years 1922, 1926-1927, 1928, 1929-1932, 1933, 1934, 1935, 1936, 1937, 1938, 1939, and 1940 respectively. In most but not all cases, maintenance costs for retardates and epileptics were not reported separately, but since most epileptics appeared to be also retarded, this should have had little effect on overall trends.

The census-derived data reported here are somewhat at variance with those tabulated by Best (1965, p. 274) for the years 1922-1960. Apparently, Best combined maintenance and capital expenditure costs for some years, and costs for retarded and epileptic residents in years where a distinction between these was possible.

Cost data derived from noncensus sources are likely to contain some errors: (1) Such data were sometimes reported in informal conferences, or as estimates. (2) I computed some cost estimates indirectly by dividing total maintenance costs in a state as reported in one reference by the total number of institution residents for the same state and year as cited in another. (3) Early reports did not always make a distinction between costs and expenditures: since many residents were partially supported by fees and subsidies, the true costs were sometimes highter than the appropriated expenditures. (4) Early maintenance figures sometimes did not include some costs later subsumed under maintenance, such as clothes. However, most of these errors are likely to result in underestimates for the early years, and thus accentuate the trend this appendix is trying to document, viz., the decline in expenditures from the early days of institutions to the end of the indictment period.

The cost data are presented in two tables. The first one breaks costs down by state between 1878 (when data apparently first began to be reported in national publications) and 1931. In some instances in Table 1, the figures apply only to one of several institutions within a state. The second table reports costs between 1926 and 1966 for the country as a whole because 1926 marked the beginning of annual nationwide cost surveys. In both tables, mean or median costs are listed both in reported dollar values, as well as in terms of 1967 dollar value equivalents as derived from cost of living indices. The reason for the conversion of costs into 1967 dollar values was to obtain a truer picture of cost trends. It should be pointed out, however, that the conversion has its shortcomings, and it is possible that the 1967 equivalents increasingly underestimate as one goes back in time. However, the general trends apparent in Figure 2 are probably valid. Finally, be it noted that crossed out spaces in Table 1 indicate that an institution did not exist in the year indicated.

A special word is in order on costs in Howe's institution, the first one to be publicly support (Third and Final Report, 1852). Massachusetts granted $7500 for a 3-year period, additional receipts being $3,808. Apparently, only a fraction of the total of 32 residents admitted were in residence more than one year. I would estimate from the somewhat vague wording of the report that the average daily census might have been 20. This means that annual per capita maintenance costs must have been about $188. Whether any of this was used for capital expenditure is doubtful, since in the transition from the experimental to the permanent phase, items that had been bought were sold again. Also, Howe (p. 21) clearly states that the money expended was equivalent to that required to teach "hundreds of children in the common schools."

Table 1

Per Capita Maintenance Expenditures in United States Public Institutions for the Mentally Retarded, By State, for 1878 to 1931

	States	1878	1879	1880	1881	1882	1883	1884	1885	1886
1.	Alabama	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
2.	California	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx		
3.	Colorado	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
4.	Connecticut							129		130
5.	Delaware	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
6.	Dist. Columbia	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
7.	Florida	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
8.	Illinois		240[3]					200		180
9.	Indiana	xxxxxx								127
10.	Iowa									163
11.	Kansas	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx		159		250		
12.	Kentucky							193		
13.	Louisiana	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
14.	Maine	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
15.	Maryland	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
16.	Massachusetts								169	169[2]
17.	Michigan	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
18.	Minnesota	xxxxxx								
19.	Mississippi	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
20.	Missouri	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
21.	Nebraska	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
22.	New Hampshire	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
23.	New Jersey	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
24.	New York									
	a) Craig	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
	b) Newark		155							
	c) Rome	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
	d) Syracuse	167[4]	161	152						168[3]
25.	North Carolina	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
26.	North Dakota	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
27.	Ohio				165		166	165	165	163
28.	Oklahoma	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
29.	Oregon	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
30.	Pennsylvania			176				217[1];160[2]	282	214;161[2]
31.	Rhode Island	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
32.	South Carolina	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
33.	South Dakota	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
34.	Texas	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
35.	Vermont	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
36.	Virginia	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
37.	Washington	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
38.	Wisconsin	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
39.	Wyoming	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
	Median	167	161	164	165	159	166	193	169	163
	Mean									
	1967 $ Value	702	685	689	668	621	689	843	754	721

[1] Higher functioning or colony resident only.

[2] Severely retarded only.

[3] Low estimate; exclusive of items such as clothing and building maintenance.

[4] Possibly a high estimate.

	1887	1888	1889	1890	1891	1892	1893	1894	1895	1896	1897
1.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
2.		300	277			197	218	183	193^3		170^3
3.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
4.											
5.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
6.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
7.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
8.						172		149			
9.		120	109			182	181^3	191			
10.	156					161^3	178	162			
11.	214		184		175	174	171	140		168	174
12.		150	227					211			
13.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
14.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
15.	xxxxxx					162	150				
16.					167	158	157	140			
17.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx					193
18.		215		187		166	167	187			183
19.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
20.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
21.				197	261	211^3	151				167
22.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
23.	xxxxxx							251			
24.											
a)	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx		
b)		126			123	111		116			130
c)	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx			
d)						182		175			144
25.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
26.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
27.	158					121		138			
28.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
29.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
30.	200	175	175	175	165		152	179			190
31.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
32.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
33.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
34.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
35.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
36.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
37.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
38.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	
39.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx
Median	179	162	184	187	167	169	167	175	193	168	172
Mean 1967 $	792	698	793	806	739	738	746	803	885	760	768

	1898	1899	1900	1901	1902	1903	1904	1905	1906	1907	1908
1.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
2.		173									
3.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
4.	197										
5.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
6.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
7.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
8.						270					
9.					136						
10.											
11.			185								
12.											
13.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
14.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx		
15.											
16.											
17.					238						
18.											
19.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
20.	xxxxxxxxxx	xxxxxxxxxx									
21.											
22.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx						
23.	194			185	267						
24.											
a)						152[1]					
b)											
c)											
d)											
25.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
26.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx					
27.											
28.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
29.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx		
30.	217				175	200					
31.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx		
32.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
33.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx							
34.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
35.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
36.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
37.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
38.											
39.	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx	xxxxxxxxxx
Median	197	173	185	185	206	200					
Mean 1967 $	879	755	777	758	824	763					

	1909	1910	1911	1912	1913	1914	1915	1916	1917	1918	1919	1920
1.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx		
2.												
3.							361					
4.							251					
5.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx
6.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx
7.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx
8.							159					
9.												
10.							174					
11.							147					
12.							229					
13.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx			
14.							267					
15.							177					
16.							192					
17.												
18.												
19.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	
20.												
21.							148					
22.	195											
23.							216					
24.							174					
a)												
b)												
c)										150		
d)												
25.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx			308					
26.							216					
27.							142					
28.							247					
29.							217					
30.							216					
31.							348					
32.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx			
33.							216					
34.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx				
35.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx						
36.	xxxxxxxx	xxxxxxxx										
37.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	184					
38.												
39.	xxxxxxxx	xxxxxxxx	xxxxxxxx									
Median	195						216					
Mean							183					
1967 $	720						706					

	1887	1888	1889	1890	1891	1892	1893	1894	1895	1896	1897
1.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
2.		300	277			197	218	183	193[3]		170[3]
3.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
4.											
5.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
6.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
7.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
8.						172		149			
9.		120	109			182	181[3]	191			
10.	156					161[3]	178	162			
11.	214		184		175	174	171	140		168	174
12.		150	227					211			
13.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
14.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
15.	xxxxx					162	150				
16.					167	158	157	140			
17.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx					193
18.		215		187		166	167	187			183
19.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
20.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
21.				197	261	211[3]	151				167
22.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
23.	xxxxx							251			
24.											
a)	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx		
b)		126			123	111		116			130
c)	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx				
d)						182		175			144
25.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
26.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
27.	158					121		138			
28.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
29.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
30.	200	175	175	175	165		152	179			190
31.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
32.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
33.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
34.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
35.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
36.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
37.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
38.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	
39.	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx
Median	179	162	184	187	167	169	167	175	193	168	172
Mean 1967 $	792	698	793	806	739	738	746	803	885	760	768

	1898	1899	1900	1901	1902	1903	1904	1905	1906	1907	1908
1.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
2.		173									
3.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
4.	197										
5.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
6.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
7.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
8.						270					
9.					136						
10.											
11.			185								
12.											
13.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
14.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx		
15.											
16.											
17.					238						
18.											
19.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
20.	xxxxxxxxx	xxxxxxxxx									
21.											
22.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx						
23.	194			185	267						
24.											
a)						152^1					
b)											
c)											
d)											
25.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
26.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx					
27.											
28.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
29.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx		
30.	217				175	200					
31.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx		
32.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
33.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx							
34.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
35.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
36.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
37.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
38.											
39.	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx	xxxxxxxxx
Median	197	173	185	185	206	200					
Mean											
1967 $	879	755	777	758	824	763					

	1909	1910	1911	1912	1913	1914	1915	1916	1917	1918	1919	1920
1.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx		
2.												
3.							361					
4.							251					
5.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx
6.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx
7.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx
8.							159					
9.												
10.							174					
11.							147					
12.							229					
13.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx			
14.							267					
15.							177					
16.							192					
17.												
18.												
19.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	
20.												
21.							148					
22.	195											
23.							216					
24.							174					
a)												
b)												
c)										150		
d)												
25.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx			308					
26.							216					
27.							142					
28.							247					
29.							217					
30.							216					
31.							348					
32.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx			
33.							216					
34.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx				
35.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx						
36.	xxxxxxxx	xxxxxxxx										
37.	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	xxxxxxxx	184					
38.												
39.	xxxxxxxx	xxxxxxxx	xxxxxxxx									
Median	195						216					
Mean							183					
1967 $	720						706					

	1921	1922	1923	1924	1925	1926	1927	1928	1929	1930	1931
1.						223	241	291			
2.		297				257	262	262			
3.		385				366	375	395			
4.		503				610	611	559			
5.		462				364	354	335			
6.	xxxxxx	xxxxxx	xxxxxx	xxxxxx	xxxxxx	664	846	696			
7.		389				454	416	326			
8.		276				229	357	260			
9.		206				223	214	233			
10.		558				257	319	301			
11.		194				282	293	287			
12.		253				225	240	215			
13.		390				283	358	342			
14.		379					332	336			
15.											
16.		333				359	371	348			
17.		525				283	306	287			
18.		240				250	256	254			
19.		714				321	285				
20.		533				580					
21.		142				193	187	189			
22.		320				349	349	345			
23.		343				389	402	434			
24.		287				332	332	344			
a)						356					
b)						303					
c)						305					
d)						374					
25.		359					288	262			
26.		312				330	318	331			
27.		188				218	217	225			
28.						206	176	190			
29.		166				208	207	246			
30.		270				249	296	297			
31.		359				402	323	309			
32.		386				312	301	280			
33.		383				468	523	433			
34.		203				257	242	204			
35.		304				279	261	260			
36.		204				177	184	190			
37.		451				200	206	430			
38.		263				311	307	287			
39.		184				317	253	396			
Median											
Mean		306				289	304	301	281	265	288
1967 $		606				542	581	582	544	526	627

Table 2

Mean Per Capita Maintenance Expenditures in United States
Public Institutions for the Mentally Retarded
1926 - 1966

Year	Per Capita Maint. Expend. National Average	Per Capita Maint. Expend. in terms of 1967 $ value
1926	289	542
1927	304	581
1928	301	582
1929	281	544
1930	265	526
1931	288	627
1932	263	638
1933	238	610
1934	237	587
1935	252	609
1936	259	620
1937	279	644
1938	296	696
1939	299	714
1940	291	690
1941	288	649
1942	315	640
1943	347	665
1944	365	689
1945	386	712
1946	434	739
1947	528	787
1948	631	873
1949	698	976
1950	746	1032
1951	807	1035
1952	920	1154
1953	980	1219
1954	1039	1287
1955	1093	1359
1956	1166	1428
1957	1280	1516
1958	1409	1623
1959	1503	1716
1960	1660	1868
1961	1742	1939
1962	1859	2045
1963	1995	2167
1964	2219	2381
1965	2380	2513
1966	2611	2676

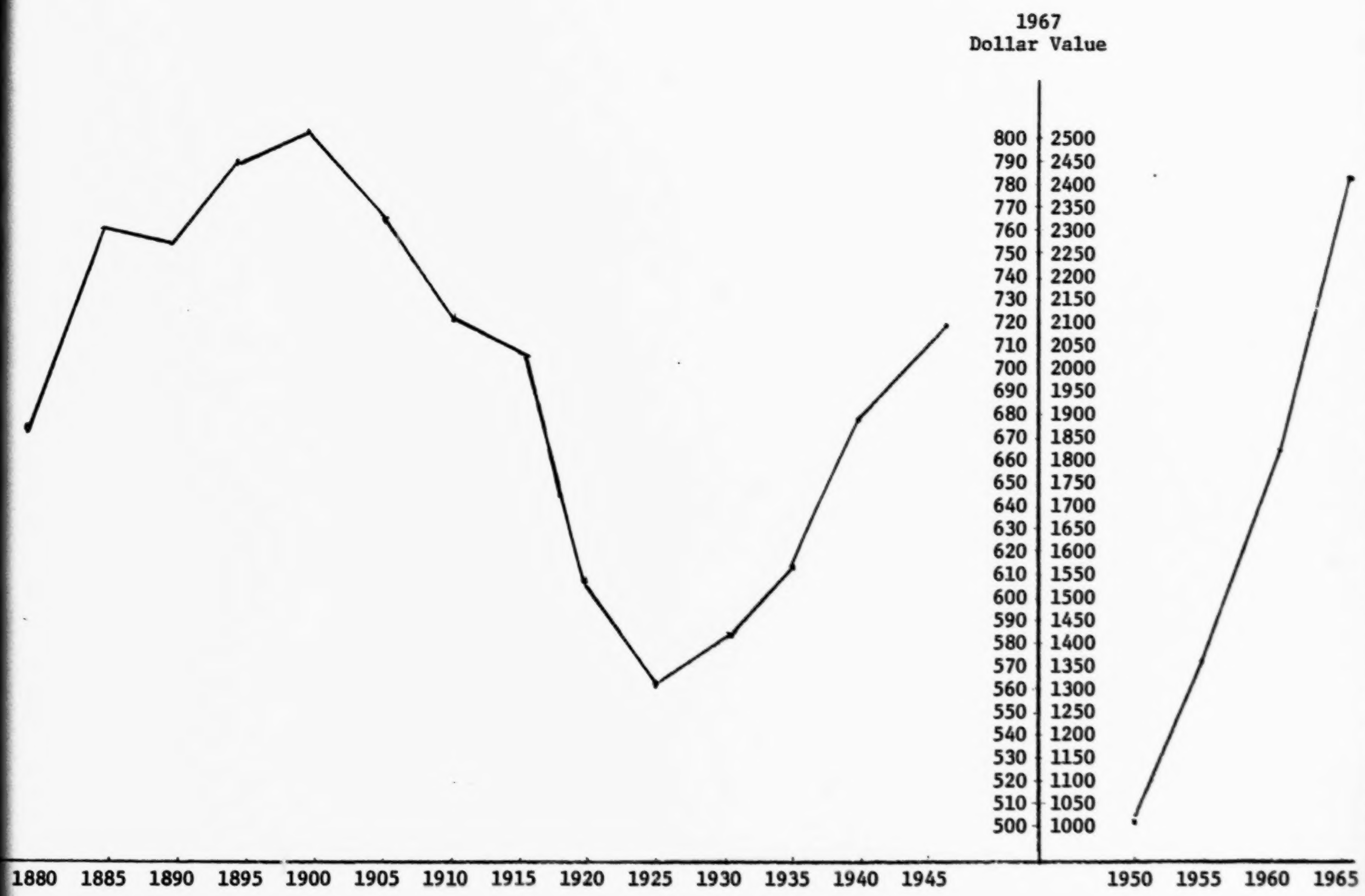

Figure 2: Five-Year Averages of Annual Per Capita Maintenance Costs of Publicly Supported U.S. Institutions For the Mentally Retarded, 1878 - 1967, in Terms of 1967 Dollar Values

APPENDIX 2

Origins of Certain Institutional Features

When we look at our institutions today, we are sometimes baffled by certain features we perceive. In the review of historical material relevant to Chapters, I came across material that explains many of these features. Appendix 2 will present some of this material which underlines several of the points made in the chapter.

The incredible catch-all nature of the institution developed in the pity period; as usual, it was rationalized to be of benefit to the resident: "The probability is that, because of the peculiar adaptation of feeble-minded persons to a community organization, State institutions may be created to embrace the care of all whose dependence needs it, and inclusive, too, of all the multiform grades; for it seems despotic to omit those who are epileptic, paralytic, or choreic, permitting a physical impediment to bar the individual from beneficial influences to which he is as responsive as any. This all-comprehending care has been contemplated in Pennsylvania under the suggestion of an asylum village to be developed from the nidus already existing at Elwyn" (Kerlin, 1884, p. 259).

Monotony of design was advocated by Sprattling (1903, p. 265): "...at the Craig Colony, in New York, under the advice of eminent architects, thirty-seven cottages, comprising the main groups in the male and female divisions, are similar in exterior design and internal arrangement..." Sprattling also advocated elimination of risks in the environment, such elimination being characteristic of the subhuman and medical models: "Some special constructional features should be incorporated, the more prominent of these being stairways broken by landings, to prevent patients from falling the entire length. All woodwork should have the sharp corners and angles broadly rounded to lessen the danger of cuts from falls during attacks; and all steam and hotwater pipes and radiators should be effectually covered or guarded, to prevent burning during coma following a seizure" (Sprattling, 1903, p. 266).

Sometimes we wonder where the term and concept of "back ward" comes from. During the pity period, when institutions experienced their first major enlargments, Pennsylvania erected two clusters of buildings for 500 residents. These clusters were a third of a mile apart, and the furthermost was reached by means of a narrow gage railway. That remote cluster of buildings housed the more severely retarded residents. The same concept of moving the most deviant person the farthest away is apparent in the following excerpt: "Before a blow is struck in the building of a colony, a definite plan of development should be laid out by making a complete topographical map of the colony estate, always remembering the value of approximating the main features; and we may illustrate the methods of doing this by drawing a circle of sufficient diameter and putting in it the office building, the hospital, the laboratory, the chapel, the laundry, schools, storehouses, industries, library, and some employes' homes. Then draw another circle and let that embrace homes for the better class of patients; then a third for patients of the great middle class, and beyond that still the homes of cases relegated to infirmary care" (Sprattling, 1903, pp. 269-270).

One of the most extensive treatises on institutional design was offered by Wallace (1924). His proposals incorporate many principles of the subhuman and medical models: "The plan I have the honor of presenting to the Association today through the courtesy of the Board of Architects embodies the plan of the Wrentham State School as prepared 15 years ago, brought up to our present conception of what a plan for a School for the Feeble-Minded should be today by the addition of certain buildings which experience has convinced the writer are necessary to properly round out the institution.

"In presenting this plan the writer makes no claim of originality. In the working out of it, he is deeply indebted to builders of institutions in widely separated sections of the country. Especially is he indebted to his old Chief, the Dean of this Association. Many of you who have visited Waverley will recognize the adaptation of the Waverley dormitory buildings in this plan.

"...the Board of Architects, with whom it has been the writer's pleasure to work in developing this plan, has specialized in institutional construction for over 30 years" (pp. 266-268).

"The type of construction should be first class fire proof throughout,...using stone for foundation, outside steps, window sills, and water tables, using brick, hollow wall construction for the super structure and reinforced concrete for all floors and verandas, and using either brick or concrete for all cross walls with door frames made fast by strong anchors securely built into the masonry. Terra cotta or hollow tile construction should not be used for cross walls, as it is too brittle to stand the slamming of doors. If it is used, the door frames will work loose with a consequent breaking of the plaster around the doors" (p. 260).

"The lower five feet of all plastered walls should be Portland cement plaster which will stand rough usage without breaking" (p. 264).

"All of the electric light switches should be placed outside of the wards and dayrooms in the halls, 6 feet from the floor thus making it inconvenient for the children to meddle with them" (p.264).

"The hot water supply pipes should be of adequate size to enable bathing to be carried on simultaneously throughout the whole institution on every floor of every building. In every building in which the children live there should be placed on the hot water supply at a point beyond where the hot water is taken off for dish washing, a control or anti-scalding valve, maintaining the temperature of the water at not over 100 degrees Farenheit, thus reducing to the minimum the danger of scalding" (pp. 263-264).

"All underground steam pipes, hot water pipes, refrigeration pipes, electric light wires and telephone wires, should be carried in a tunnel large enough for one to walk through and wide enough in which to properly use tools when making necessary repairs. Any other form of caring for this underground construction will, eventually, prove most costly and unsatisfactory.

"In an institution that will cost approximately $2,000,000 a tunnel to accommodate this construction will cost approximately $65,000. This cannot be considered exorbitant if looked upon as insurance against accident and deterioration, to those vital arteries through which course the heat, light and power of the institution" (p. 262).

"Much study should be given to the standardization, as far as possible, of all buildings, furnishings and equipment. It is desirable to have the buildings standardized for the largest part of the population. The window glass should be of uniform size throughout the institution. All hardware, plumbing, plumbing fixtures, faucets and all steam fixtures such as traps, and valves, should be standardized. All furnishings such as electric light fixtures, window shades, chairs, tables, bureaus, beds and bedding should also be standardized" (p. 259).

"The dormitory building can be the same for the two sexes and of standard size and construction" (p. 264).

"A standard dormitory to accommodate 105 pupils seems to combine economy of construction with efficiency in management" (p. 265).

"It is with some trepidation that I approach the problem of floors for in the history of institutional construction I presume no one subject has received more thorough discussion, yet the problem is not wholly solved...In hallways, bathrooms, diningrooms and dayrooms for adult working boys, I believe terrazzo has no equal. For adults' wards and dayrooms where very little water is required heavy battleship linoleum securely cemented to conrete underfloor may be used to advantage. For wards and dayrooms of low grade, untidy patients, where floors require frequent wiping up of spots, the rubber flooring is unsurpassed.

"In every institution, however, there is a large number of destructive patients who will move anything that is movable and destroy anything that is not indestructible.

"Linoleum and rubber flooring in a building for these patients are not satisfactory inasmuch as the patients will quickly have the linoleum and rubber separated from the under surface and broken and destroyed. In building for this class the flooring should be made of terrazzo everywhere except in the sleeping wards. Here, first class maple flooring seems to serve the purpose best. Kitchen floors should be of first quality slate, although a terrazzo floor here is satisfactory. A well troweled granolithic makes a satisfactory laundry floor. Rubber flooring throughout would make the most serviceable, quiet, and suitable covering for the school building. If this is too expensive, a satisfactory treatment is to have all halls and toilet rooms laid in terrazzo and school rooms with maple flooring. The best floor covering for the Assembly Hall is rubber. Again, if this is too expensive, heavy, battleship linoleum, securely cemented on a concrete under floor is quite satisfactory.

"In the hospital on account of its noiselessness, the ease with which it can be cared for, and because of its non-absorbent qualities, the free use of rubber flooring is justified, even though it may be expensive.... Most of the stairs throughout the institution should be steel with 1/4" rubber inset treads securely cemented in place.

"In the buildings for destructive patients, the stairs should be built of either terrazzo or concrete" (pp. 260-262).

"There are certain institution buildings where one floor construction is clearly indicated. These are infirmary and nursery buildings where there should be no steps, the floor being located at but a slight elevation above the outside grade, and the building entered by means of slightly graded ramps. The laundry buildings should be on one floor, consisting of one large room. This makes the supervision by one person easily possible" (pp. 265-266).

In contrast to the specification for residents' living units stand the guidelines for employees' living quarters: "In planning and developing an institution it is of vital importance that the living quarters of the employees should have due consideration. No matter how Utopian a State Government, Board of Trustees, Superintendent or Medical Staff may be in their expressed desire of what shall be done for the benefit of the children in the institution, what is actually accomplished is what the employees do for the children. The higher the scale of intelligence and the higher the living ideals of the employees of an institution the higher degree of service will they render in caring for the children. Hence, how important it is to make housing and living conditions such as will attract to the service and retain in the service, the highest type of employee. Small, attractive, homes to accommodate about 20 employees each should be conveniently located throughout the grounds. These should consist of single room arrangement with good bath and toilet conveniences provided and a common reception room. These small homes make possible the gathering together of groups of congenial people. There should also be provided a number of small cottages for married employees. There should be a recreational center, --in fact, an up to date, well furnished club, consisting of a large common lounge, reading room, smoking room, pool room, bowling alleys, and a store. The officers' quarters should be a little village of small houses that could be occupied by the families of married officers or five to seven single officers. In this center should be a building designed for kitchen, dining room and recreational purposes" (p. 266).

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Part V: Toward New Service Models

Chapter 6

Recommendations for Institutional Reform

Burton Blatt
Massachusetts Department of Mental Health

RECOMMENDATIONS FOR INSTITUTIONAL REFORM

In an earlier section of this monograph I have described my reactions to conditions widely encountered in American institutions for the retarded. Below, I am offering a number of recommendations.

My recommendations derive from many sources: my experiences prior to this study, what I observed during the study, the reactions of many astute individuals to this study, and the advice of students and colleagues. In addition to the emergency need for at least doubling per capita expenditures in state institutions and for reducing the sizes of institutional populations wherever and however possible, my study of this problem leads to an additional set of recommendations that may contribute to an improvement of institutional programs and facilities:

1. In each state, a board of institutional visitors should be appointed by the governor or other constituted authority. This board would be responsible for reporting directly to the highest state officials. Appointments to this board would be made irrespective of political party affiliation, and these appointments should be contingent on both knowledge of the broad field of human welfare and demonstrated public service. Members of this board of visitors would not be, concurrently, members of any particular institution's staff or board of trustees.

2. Within each state institution for the mentally retarded, each department (e.g., medical, psychological, educational, nursing, cottage life) should have a board of advisers. This board of advisers, through periodic visits and consultations, would know the institution and its problems intimately and thus be in a position to advise and assist in the resolution of difficulties. In essence, the advisory board would be organized for direct consultation and assistance to the institutional staff. As this board would not be responsible for rating institutional personnel or recommending their salary increments or promotions, it is possible that members of this board would become involved with the most pressing and severe problems of the institution--without "endangering" the positions of the staff that trusts them. In this way, it would be possible for problems currently secreted from the outside world to be given the exposure and ventilation needed for satisfactory solutions to them.

3. Can one any longer ignore the needed relationship between the state institution for the mentally retarded and the state university? In each state, a state university should be given responsibility and resources to provide comprehensive in-service training and consultation for all institutional employees, from the chief administrative officer to the rawest attendant recruit.

4. In each state, at least one state institution for the mentally retarded should be designated as a center for the in-service training of all personnel to be employed for state service in institutions and clinics for the mentally retarded. As a condition for employment as institutional superintendent, psychologist, teacher, nurse, or attendant the candidate would have to spend a specified period of time at the training center. His preparation program would range from a few weeks to one calendar year, depending upon his background and experiences and the nature of the position he intends to assume. During this training program the candidate would be involved in clinical experiences that relate directly to his future employment, would participate in seminars, colloquia, and other instructional experiences designed to prepare him for the sensitive and demanding activities of work with the mentally retarded. At the end of the candidate's training program, the director of this facility and his staff would rate the candidate and recommend him or not recommend him for employment. To the degree that this program is workable with currently employed staff, every inducement and encouragement should be provided to permit them to complete this preparation.

There is a shame in America. Countless human beings are suffering--needlessly. Countless more families of these unfortunate victims of society's irresponsibility are in anguish, for they know, or suspect, the truth. Unwittingly, or unwillingly, they have been forced to institutionalize their loved ones into a life of degradation and horror.

I challenge every institution in America to look at itself, now! I challenge each institution to examine its program, its standards, its admission policies, its personnel, its budget, its philosophy, its objectives. I challenge every institution--and every governor and every legislator--to justify its personnel and their practices, its size and development, and its budget.

My experiences during Christmas 1965 require me to call for a national examination of every institution for the mentally retarded in America--an examination that will inspect the deepest recesses of the most obscure back ward in the least progressive state. I call for a national examination of state budgets for the care and treatment of the retarded. I hold responsible each superintendent, each commissioner of mental health, each governor, each thoughtful citizen for the care and treatment of individuals committed for institutionalization in their state.

To some degree, all of us talk and behave as if we will not change. Yet, it is abolutely certain that we will change; what we profess now, in one way or another, we regret later. By this I mean that the most difficult truth each of us has to learn and live with is the knowledge that we are not perfect. It was my intent in this article to point out some of the more serious imperfections of state institutional programs for the mentally retarded in this country. It is my belief that, now that our most indefensible practices have been laid bare for public scrutiny, men of good will from all walks of life and all professions will sit down at the planning table and seek solutions to the plight of our brethren.

Part V: Toward New Service Models

Chapter 7

The Normalization Principle and Its Human Management Implications

Bengt Nirje
Swedish Association for Retarded Children

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THE NORMALIZATION PRINCIPLE AND ITS HUMAN MANAGEMENT IMPLICATIONS

The Normalization Principle

In an earlier section of this book I have described some observations and reactions upon visiting public institutions in the United States. I will now attempt to describe the theoretical perspective from which my reactions to my observations stem.

My entire approach to the management of the retarded, and deviant persons generally, is based on the "normalization" principle. This principle refers to a cluster of ideas, methods, and experiences expressed in practical work for the mentally retarded in the Scandinavian countries, as well as in some other parts of the world. The normalization principle underlies demands for standards, facilities, and programs for the retarded as expressed by the Scandinavian parent movement. The papers by Scandinavian contributors Bank-Mikkelsen and Grunewald in this monograph provide specific descriptions of functioning programs which incorporate normalization principles.

To discuss human endeavors to create wholesome programs, facilities, and life conditions for other human beings in terms of one unifying principle might seem preposterous, especially when the mentally retarded are involved, a group which is characterized by wide variations in age, degree of handicap, complicating physical and emotional disorders, social backgrounds, and educational and personality profiles. Nevertheless, in the Scandinavian countries, a general principle which expresses the aims, attitudes, and norms implied in quality work for and with the mentally retarded has been found of value. As expressed by N.E. Bank-Mikkelsen of Denmark, this principle is given in the formula "to let the mentally retarded obtain an existence as close to the normal as possible." Thus, as I see it, the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.

This principle should be applied to all the retarded, regardless whether mildly or profoundly retarded, or whether living in the homes of their parents or in group homes with other retarded. The principle is useful in every society, with all age groups, and adaptable to social changes and individual developments. Consequently, it should serve as a guide for medical, educational, psychological, social, and political work in this field, and decisions and actions made according to the principle should turn out more often right than wrong. Some of the many facets and implications of the normalization principle are discussed below.

1. Normalization means a normal rhythm of day for the retarded. It means getting out of bed and getting dressed even when you are profoundly retarded and physically disabled. It means eating under normal circumstances: sometimes, during the span of the day, you may eat in large groups, but mostly eating is a family situation which implies rest, harmony, and satisfaction. A normal daily rhythm also means not having to go to bed earlier than your peers because you are mentally retarded, not earlier than your younger sisters and brothers, or not too early because of lack of personnel. Facilities must also give consideration to the individual's need for a personal rhythm, allowing him to break away occasionally from the routine of the group.

2. The normalization principle also implies a normal routine of life. Most people live in one place, work or attend school somewhere else, and have leisure-time activities in a variety of places. Consequently, it is wrong when a retarded person, for example, has his training classes, his structured therapies, and his recreation activities in the same building that serves also as his "home." Of course, even when vocational activities are conducted in a special building, it is not satisfactory if this consists only of a few hours of low-motivated activities for a few days a week. Activation of the mentally retarded, which is all-important, must convey the experience that the daily work routine has vigor and meaning and, consequently, fills a proper part of the day. The afterwork satisfactions of leisure-time activities, whether they are for pure relaxation and fun or have more personal, educational implications, may sometimes take place in institutional or special settings, but for habilitational purposes, use should also be made of the facilities of the regular society, thus lending these activities realism. With wider experiences and proper social training, the retarded thus will be able to use the normal leisure-time facilities of his society on his own, and also learn to cope with unprepared, unstructured situations without panicking (Avedon, 1967; Chigier, 1967; Nirje, 1967).

3. Normalization means to experience the normal rhythm of the year, with holidays and family days of personal significance. Most people change their life situations and refresh their bodies and minds at least once a year by going on vacation. In Scandinavia, travel, including travel abroad, has proved meaningful and valuable even for the severely and profoundly retarded.

4. Normalization also means an opportunity to undergo normal developmental experiences of the life cycle:

a. Children should have available warmth of atmosphere, rich sensory stimulation and surroundings, and settings of proper proportions. Handicapped individuals especially need to be fed with stimuli which will nourish knowledge and abilities. In cases where a retarded child cannot live with his own family, this aspect is of special importance. In normal society, small children live in a world especially structured for them, guided and taught by a few significant adults. In child-care homes, turnover of personnel should be minimal, thus offering the children basic security and opportunities for identification of the stand-in parents. These essential demands have proved almost impossible to realize in large heterogeneous institutions, where one is confronted with the specific attitudes of the personnel and the adult retarded. It is therefore completely wrong to let mentally retarded children live in the same institutions as retarded adults.

b. Youths of school age in normal society also live in a world specifically structured for them. Childhood is a highly developmental period of great importance for learning about one's own personal abilities and potentialities, for obtaining understanding of oneself, and for building self-confidence that can serve as a sound basis for life after the school years. It is also a period during which social experiences outside the classroom are very important for personal stimulation and development. Youngsters and adolescents of school age who are retarded should therefore never live in a confined setting together with mentally retarded adults, because the young people's socialization and impressions of life should be gained as much as possible through contacts with normal rather than a deviant society.

c. For the mentally retarded, growing from adolescence into adulthood is often a longer, more painful, and more uncertain process than for others. Their image of themselves often becomes warped and confused. They are not always accepted, treated, and respected as adults. Here, the attitudes expressed toward them by others are of utmost importance, whether these others are parents, relatives, or institution personnel. Thus, like everybody else, the retarded should experience the coming of adulthood through marked changes in the settings and circumstances of their lives. Just as it is normal for children to live with their parents, so it is normal for adults to move away from home and start a life of their own, as independently as possible. Therefore, it is wrong for mentally retarded adults to live on the same premises as children and youngsters, because this serves as a constant reminder that they are different from other adults, and that they are as dependent as children. Training programs for retarded young adults should assist them to become as competent and independent in their personal daily routine as possible, and to develop social skills which will enable them to take part in the regular community life as much as they can.

d. The period of old age, when work is no longer possible or feasible, consists for most people of contacts with the familiar settings and acquaintances that have given life so much of its content and meaning. Therefore, alternate living facilities for the aged retarded should be arranged close to the place where they have spent their adult periods of life, in case they cannot remain in that very place.

5. The normalization principle also means that the choices, wishes, and desires of the mentally retarded themselves have to be taken into consideration as nearly as possible, and respected. In May 1968 a conference was arranged for mentally retarded young adults, IQs about 35-70, from eight cities in Sweden. In this conference, these young men and women, 18-30 years old, discussed vocational training and their leisure-time and vacation problems. They wanted a stronger voice in their own leisure-time programs, student clubs, and labor union participation. They objected to being included in activities with children below the age of 15 or 16, and to being in too large and too heterogeneous groups. In discussing group study tours and group vacation trips, they stressed their demand to be only in small homogeneous groups. They found communication in large groups unsuitable, as it is more difficult to hear and understand what is being communicated. Obviously, they had too often had the normal tourist experience of moving in herds.

6. Normalization also means living in a bisexual world. Accordingly, facilities should provide for male and female staff members. When it comes to the integration of retarded boys and girls or men and women, the 1967 Stockholm Symposium on "Legislative Aspects of Mental Retardation" of the International League of Societies for the Mentally Handicapped[1] came to the following conclusion: "Being fully mindful of the need to preserve the necessary safeguards in the relations between mentally retarded men and women, the members of the Symposium are of the opinion that the dangers involved have been greatly exaggerated in the past. This has often resulted in the unfortunate segregation of the sexes in an unnatural way and has militated against their interests and proper development.

"Accordingly, the Symposium strongly advocates the mixing of the sexes in a manner as free as is commensurate with normal restraints, not only in day centers and workshops, but also in leisure time activities.

"Experience in some countries indicates the advantage of mixing men and women in hostels and other residential facilities in such a way as is approximate to normal life."

Mixing of the sexes according to the normal patterns of everyday society results in better behavior and atmosphere, as more motivations are added. And the mildly retarded sometimes suffer in a loneliness that has no sense, and as others, they may be better off married.

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[1] The League is an international federation of associations of parents of the mentally retarded. The symposium, published by the League, summarizes basic principles upon which practices in the field of mental retardation should be based. These principles were derived from a definition of the rights of the mentally retarded.

7. A prerequisite to letting the retarded obtain an existence as close to normal as possible is to apply normal economic standards. This implies both giving the retarded those basic financial privileges available to others, through common social legislation, as well as any other compensating economic security measures that may be applicable. This includes child allowances, personal pensions, old age allowances, or minimum wages. Of these allowances, the larger part may be used for board and lodging, but a normal amount of pocket money for the individual's private use should be given regularly, both to assist in realistic social training and to help foster independent choices. Work that is done in competitive employment, in sheltered workshops, or within institutions should be paid for according to its relative worth.

8. An important part of the normalization principle implies that the standards of the physical facilities, e.g., hospitals, schools, group homes and hostels, and boarding homes, should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens. Application of these standards to facilities of various types imply a number of important specifics:

a. It means that the sizes of facilities should conform to what is normal and human in society. Especially, it should be kept in mind that a facility for the retarded should never be intended for a larger number of persons than the surrounding neighborhood readily assimilates in its regular everyday community life.

b. It further implies that in planning the location of these facilities, they should never be placed in isolated settings merely because they are intended for the mentally retarded.

With normal locations and normal sizes, facilities for the mentally retarded will give their residents better opportunities for successful integration.

Some Benefits of the Normalization Process

All the above-mentioned facets of the normalization principle make a normalization of the life situation of individual retardates quite feasible: the normalization process can aid many in achieving complete independence and social integration; a great number will be helped in developing relative independence though they may always need various kinds of assistance to various degrees; even the relatively few who are severely or profoundly retarded, or who are afflicted with complicating medical, psychological, or social handicaps will, no matter how dependent they may be, have life conditions, facilities, and services that follow the normal patterns of society.

For the retarded child, adolescent, and young adult, almost every situation has pedagogical implications, possibilities, and values. Just as the right of education is important for every citizen, so it is important for the mentally retarded to have a right to equal opportunities for education, training, and development.

Development of various abilities always has bearings on the development of the whole person. Development of the retarded therefore places particularly heavy responsibilities on persons in charge of the life conditions of the retarded. Mental retardation as a handicap creates especially high frustrations and hurdles for the individual, thereby making it even more urgent to assist and stimulate the retarded in the building up of his self-confidence.

Through stimulating and rich experiences, he can experience himself as an active agent while sensory deprivation imposes a further handicap. To develop a feeling of personal identity is an essential growth factor, and thus the experience of being nameless and anonymous is dangerous and damaging. The self-image of the retarded must be built on letting him experience his personal abilities; thus experience of rejection and disregard creates confusion, stress, and unhappiness.

To develop self-regard, the retarded person must learn how he can succeed through his efforts to cope and thereby to obtain experiences of responsibility. Thus, a too sheltered and barren environment which does not allow for personal activities too often leads to experiences of failure and of being without status and value. The development of a feeling of personal dignity can determine the degree of self-control established, while the experience of lack of regard from others is threatening and corroding.

All these factors coincide decisively when the retardate in his development comes to the state of accepting himself as an adult and as a responsible person with a realistic self-confidence. These points are the more important, as becoming adult for the mentally retarded also means coming to terms with his own awareness of being mentally retarded (Cobb, 1966).

As almost every situation for the mentally retarded has a pedagogical significance and often is related to his slow building up of a self-concept, it is essential that the mentally retarded should be offered appropriate facilities, which assist his educational processes and development and which make it possible for him to experience himself as becoming adult in his own eyes and in the eyes of others. This is a basic requirement for helping his life development come as close to the normal as possible.

Large institutions and the conditions we can observe in their back wards can never offer facilities of the kind and quality that are essential. In the large wards, the rhythm of the day reduces the retarded to an object in an empty, machinelike atmosphere. The normal rhythm of daily routines of occupation, leisure, and personal life is emasculated to surrogate activities, not integrated with a meaningful personal existence. The normal rhythm of the year is mostly dwarfed through the experience of monotonous confinement. The development of individuality is helplessly mutilated and crushed in a life in herds.

Application of normalization principles has profound implications not only to the retarded but also to the public, to those who work with the retarded, and to the parents of the retarded.

When residential facilities for mentally retarded children are constructed, located, operated, and interpreted as homes for children; when special schools for the mentally retarded are integrated into regular schools or are looked upon as no more than schools for children and youth; and when group homes and hostels for the adult retarded are looked upon mainly as homes for adults; then such direct and normal experiences will result in a normalization of society's attitudes toward the retarded. Isolation and segregation foster ignorance and prejudice, whereas integration and normalization of smaller groups of mentally retarded improve regular human relations and understanding, and generally are a prerequisite for the social integration of the individual.

Normalizing a mental retardation setting also normalizes the working conditions of the personnel. Workers perceive the retardate, his role, and their own roles in entirely different ways. In turn, the workers themselves are perceived differently by society. They enjoy a higher status and gain in self-respect. Almost always, an increase in work efficiency and effectiveness is one of the results.

Application of normalization principles also can serve to normalize the parents' situation. When residential centers, group homes, and schools of normal standards, sizes, and locations are available, as well as day centers and workshops, the parents of the retarded can choose placements according to the individual needs of the retarded person and the needs of the family. Their choice of placement can be accomplished freely and with an easier mind, rather than being an anguished and forced choice between the horrible and the impossible.

The closer persons in the decision-making bodies of society come to the mentally retarded, the more likely they are to render decisions resulting in appropriate and efficient programs. It may be sobering to many Americans that in Sweden, programs based on normalization principles are not dreams but actual realities brought about by the decisions of "hard-headed" penny-pinching county council appropriation committees. For those who are interested in how normalization principles have been embodied in Swedish legislation, details are provided in the Appendix.

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APPENDIX

THE NORMALIZATION PRINCIPLE IN SWEDISH LAW

The normalization principle has grown out of Scandinavian experiences in the field, both from mistakes and errors of the past as well as from planning and development of new and better programs. The new

Swedish law on mental retardation, effective as of July 1, 1968, can be seen as an expression of the normalization principle. This "law about provisions and services for the mentally retarded," dated December 15, 1967, is printed in the Swedish Code of Statutes 1967 (Svensk Författningssamling), No. 940, published on January 31, 1968. The law can be viewed as a Bill of Rights for the mentally retarded, being based on what their rights are believed to be. It provides for a wider range of services, and stresses that these services should be given to each retarded person according to his personal needs.

The new law is more comprehensive than the previous one of 1954, and covers a wider range of community services for the mentally retarded. It not only reflects developments which have actually taken place but also shows a new line of thought concerning what county councils must do to bring about radically improved conditions. Some sections of the law are summarized, discussed, and interpreted below.

Section 1: "This law concerns those who, due to retardation in their mental development, need special care and services from the community for their education, training, and integration in the community."

If there is a need for the provisions listed in the law, there is also a right to receive them. Through this general wording, it is possible to provide borderline cases, for instance, former wrongly placed students of remedial classes for slow learners, in the regular school system with the services they may need.

Mental retardation is not necessarily seen as a life-long condition. If, for instance, it is possible for a person to manage without the care and services of the community after special school and training for daily living, this person is no longer considered mentally retarded.

The previous law dealt mainly with the institutions the county councils had to establish. The new law has sections on both residential services and nonresidential services such as education and training. These provisions do not exclude but are complementary to one another.

Section 4: "Residential institutions, special hospitals, day centers for children, and occupational centers shall be provided for the care of the mentally retarded, and there shall be special residential institutions for those mentally retarded who need care in residential institions with special arrangements.

"Mentally retarded who need care according to this law, but who do not need care in an institution as referred to above in the first section, shall be provided with care in their own homes."

Thus, mentally retarded who live with their parents shall have access to day centers for children, or occupational centers for adults, with the care, training, and therapy being equal to the standards of good residential care institutions. The county councils have so far concentrated on various residential facilities, but a great deal has to be accomplished in Sweden in order to surpass, for instance, England in the matter of developing and extending nonresidential service facilities.

The right to be provided with services at home--involving one or several persons who visit the home regularly to give care and provide training or occupational activities--will, of course, serve as an additional spur to the county councils to invest in day centers and occupational centers.

Section 4 has been written so that parents, so far as possible, will be free to choose between different services and be able to decide on either care within or outside the home, according to the estimated needs of the mentally retarded and the family circumstances.

Section 5 contains one of the great new features of the law:

Section 5: "Accommodation in other private homes, boarding homes or student hostels shall be provided for those mentally retarded who cannot stay in their own homes but who do not need to live in a residential care institution or a special hospital."

Those who do not need to live in residential institutions should not. It is just as normal for an adult to live as independently as possible as it is for a child to live with his parents. Thus, society has to provide other accommodations as close to normal as possible. This rule is of special interest to older parents whose retarded children have grown up and can manage without too much supervision. In the future, there will be boarding homes not only for those working on the open market but also for those working in sheltered workshops or occupational centers who can manage without the more extensive care provided by a modern residential institution.

All the mentally retarded below school age have a right to preschool training. At age seven, compulsory school starts and includes both "educable" programs for the mildly and some of the moderately retarded children (IQs between about 45 and 70) and "trainable" programs for most of the moderately and some of the severely retarded (IQs between about 25 and 50). Education is to be given for 10 years, followed by compulsory vocational school attendance up to age 21, which can be prolonged to age 23 in certain instances. Relevant sections of the law follow:

Section 24: "Special school attendance is compulsory for mentally retarded who can profit from education, but who are unable to participate in educational training within the general education scheme.

"Such compulsory education starts from the autumn term of the calendar year when he will be seven years old, and lasts as long as he needs training, although not longer than up to and including the spring term of the calendar year when he will be 21. However, if there are exceptional reasons, this compulsory education may be prolonged up to and including the spring term of the calendar year when he will be 23."

Section 3: "School education is provided for the mentally retarded in special schools, where they also shall receive personal and medical care as needed. Special schooling includes preschool, provision for the educable and trainable, vocational training, or several of these.

"Separate classes or schools shall be provided for those mentally retarded who are able to attend special education but have difficulties in adjusting to the activities of the school, or who need special arrangements for their education. Mentally retarded who are unable to participate in the regular work of the special school, due to motor difficulties, sensory handicaps, long periods of illness, or similar circumstances, shall be provided with educational forms specially adjusted to them."

It should also be noted that compulsory education, i.e., the right to receive special school education, includes children residing in institutions and special hospitals.

Preschool education prior to the age of 7 is defined as a right of the child, but not compulsory to him. All mentally retarded children who can make use of preschool training have a right to receive it, regardless if they might later be compelled to attend special school or not. Early training is fundamental for mentally retarded children, and the county councils are counted upon to work actively in tracing these children.

The education given in educable programs (IQs 45-70) as well as in trainable programs (IQs 25-50) is intended for the ages 7-17. A new provision here concerns trainable programs intended for children who are unable to participate in educable programs, but who can make use of practical education and social training.

The right to attend school, as well as compulsory school duty, will in this way finally be implemented for those children who have, until now, been referred to "practical" classes or day centers, or who have not received any education and training at all. As a consequence of this rule, trainable programs will also be established at residential institutions for children. In other words, the law has made mandatory what is considered "trainable" education in the United States.

The autumn term of 1968 will then mean compulsory school for a larger number of retarded children and youths between ages 7 and 20 who previously did not receive any education and training at all. The county councils have a big task here. To begin with, a number of provisional measures must, of course, be approved by the authorities, but the essential fact is that there is a compulsory school duty in force from July 1, 1968. As far as the enforcement is concerned, the law, in Section 2, states: "The county council communities shall provide the mentally retarded residing within the county council community with education, care and other services made mandatory by this law, insofar as someone else does not provide for it." Section 6 states that "the activities of the county council community shall be administered in accordance with this law by a Board for the provisions for the mentally retarded. A committee which handles other administrative tasks of the county council community may be appointed to such a board." "Such Boards of provisions for the mentally retarded shall include appointments of a head of special schools, a head of care facilities, and a head physician."

Section 8 decrees that "the county council community shall draw up a plan for organizing provisions and services for the mentally retarded. This plan shall include the facilities needed for the mentally retarded." The plan shall be authorized by the King or by an authority appointed by the King. In accordance with Section 13, the Board of Education and the Board of Health and Social Welfare are the authorities responsible for the supervision of the actual implementation of the activities in accordance with the law.

Section 16 contains a summary of the tasks of the Boards for provisions:

Section 16: "The Board for the provisions and services for the mentally retarded shall:

work towards the attainment of the provisions needed by the mentally retarded residing within the county council community;

plan and coordinate the activities of the county council community according to the law, and work towards the satisfactory development of law;

administrate the facilities for the retarded which are under their management and other activities for them which are managed by the county council community, if not otherwise governed according to the second, third, and fourth paragraph of Section 6;

take charge of the local supervision of other facilities for the retarded according to the more detailed instructions given by the King;

bring before the county councils those proposals which concern provisions for the retarded as they are found to be needed."

This "energy section" of the law aims at actively engaging the Board for provisions and services for the benefit of all retarded in need of the provisions ensured to them by this law. A prerequisite for this is the dissemination of information, and active cooperation with child care centers, agencies working with the mental hygiene of children and youths, district physicians, district nurses, children's hospitals and child clinics, Swedish parents' association for the retarded, etc. The Boards for provisions shall also be responsible for the development of services in a satisfactory manner, as, for instance, the supply and training of personnel, and the application of new methods and practices in the training of the retarded and their integration into the community.

The old painful system of registration is eliminated; the new procedure will be to register at the residential institution or special hospital of residence or in the school attended. In the rest of the cases, only the Boards for provisions will only keep a record of all known mentally retarded and will there make a notice of the different kinds of provisions supplied in each special case.

While the Swedish law offers a basis for the creation of decentralized, differentiated, specialized smaller institutions, hostels, and boarding homes for the retarded, some conditions still exist in Sweden that are not consistent with the normalization principle. For example, there are still about half a dozen institutions for more than 400 persons, the largest having as many as 740 residents. These institutions, as well as some in the 200-400 range, are institutions for heterogeneous age groups from early childhood to senescence, and two of them still even have special schools on the grounds. (All the other 25 special boarding schools have independent locations.)

More than half of the mentally retarded living in institutions in Sweden do so in facilities built after 1954, when a special law on mental retardation services was enacted. These newer institutions usually provide single and double bedrooms, and occasionally 4-bed rooms. Most of the older institutions have been modernized and rearranged according to modern standards. However, there still are a few deplorable regional institutions in Sweden where the retarded have to live as many as 10 to a room, with large, inadequate dayrooms which serve as many as 25 or 30 persons. These institutions are satisfying neither to the retarded nor to the Swedish parents--nor, for that matter, to the authorities.

There are also institutions which, even with modern communications, remain isolated from the mainstream of community life. One of the main conclusions of the previously mentioned Stockholm Symposium was "that facilities for retarded persons should not be situated in remote or secluded areas, which preclude the essential contact between them and the community and which would prevent their complete integration in society."

With regard to residential accommodations, the following conclusion was reached: "The Symposium recommends that each country should determine and proclaim the desirable standards of accommodation for mentally retarded persons having regard to the following considerations:

1. that the structure of each facility planned should take into account the special needs of mentally retarded persons;

2. that facilities should not be sited in isolation, nor planned in such a manner that the mentally retarded persons for whom they are intended, would be deprived of normal contacts with the community;

3. that while there are differences of opinion as to the optimum size of multi-purpose complexes, such as residential centers which incorporate education, training and treatment functions, there is general agreement:

a. that it is much more difficult to fulfill the rehabilitation programme in all its aspects in a big institution than in a relatively smaller one;

b. that the living, dining and recreational units of such complexes should be small, with living accommodation for numbers not exceeding some 15 to 20 persons;

c. that, on the other hand, there is a necessity to determine a minimum size for each facility, commensurate with its purpose and special needs;

"It has been the experience, at least in the Scandinavian countries that large institutions tend to counteract the social integration of the mentally retarded person and militate against his individual needs for education and training and that, further in the relationship between effect and cost, the smaller unit is preferable and more economical in the final analysis."

The Symposium also stressed the necessity to ensure implementation and concluded:

"Each country should formulate and put into effect that system of control best suited to its governmental structure, in order to exercise supervision of the implementation of legal measures regarding the care, education, training and employment of retarded persons. The aims of such control should be:

a. to ensure that full coverage is provided for the retarded population, and that every retarded person regardless of his personal means or those of his parents or guardians is provided with the facilities which he needs;

b. to ensure that the standards of facilities provided are adequate and that all services conform to the standards promulgated."

Both our service structures and our service concepts must continually evolve. It is hoped that Swedish provisions will improve further so as to be fully consistent with the Stockholm and normalization principles. It is further hoped that by that time, there will be even more advanced principles to challenge us.

Part V: Toward New Service Models

Chapter 8

Residential Services Within the Service Continuum

Jack Tizard
University of London Institute of Education

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RESIDENTIAL SERVICES WITHIN THE SERVICE CONTINUUM

The President's Panel on Mental Retardation (1962) stated with admirable lucidity the problems of providing both residential and non-residential services for the retarded. These problems face not only the United States, but all advanced countries of the world. As far as residential care is concerned, there is an overall shortage of places. Despite increases in the number of beds in recent years, the waiting lists remain long. More seriously handicapped retardates, especially children, are surviving and are being admitted to residential care at an early age; the expectation of life of these severely handicapped persons has increased markedly.

This chapter has to do with residential services. But, as the President's Panel noted, residential services cannot be considered in isolation from general community services. Before considering alternatives to current models of residential care, something will therefore be said about services in general, and the factors that influence needs for residential provision.

The Epidemiological Basis for Planning of Services

In planning for the needs of the mentally retarded, it is necessary to have an idea of the population whose needs would be met by the service. A conveniently sized population to plan for is one of 100,000. Many local authorities are of about this size, and estimates worked out on a base of 100,000 can be readily adjusted to meet the needs of larger or smaller communities.

As a working rule for planning day services for people living in their own homes, I suggest that the maximum size of the area which provides a service should be one in which any member of the population is within an hour's traveling time, door to door, of any center which he should be required to attend regularly. It follows that schools, treatment centers, hospitals, clinics, workshops, and recreational facilities serving a population usually will be best placed in the center of the area in which the population lives, rather than on the outskirts. In highly urbanized areas with a good transport system giving quick and easy traveling, a population larger than 100,000 might be served by one service system, but in rural areas it may be necessary to plan for the needs of smaller populations.

In order to plan services for the mentally retarded, it is necessary to know the number of persons who will require them. Ordinary administrative statistics are an unsatisfactory guide because they merely tell us the number of cases being dealt with, but do not indicate the extent of unmet needs. Increase the amount of provision, and the numbers of "ascertained" cases increase; decrease it, and they fall. The number of beds for mentally retarded persons in the whole of India is only a few hundred. This gives no indication whatsoever as to the number of retardates who need them in that country.

Fortunately, a number of surveys of the prevalence of mental retardation have been undertaken in different Western countries in recent years (Gruenberg, 1966; Tizard, 1966). By and large, these surveys have yielded results which are highly similar as far as the rates of severe and profound mental retardation are concerned, though they differ in the rates arrived at in respect to mild mental retardation (IQ>50). Enough is known, however, about these and the factors that influence them in order to serve as a basis for action.

A finding which has emerged from all surveys of the prevalence of mental retardation is that the numbers of cases discovered differ in the various age groups of the population. Rates are low in infancy, and then rise steadily until a "peak" prevalence rate is reached during the early teens. Thereafter, there is a decline in age-specific rates with age.

There are several reasons for the increase in numbers and rates throughout childhood. First, the diagnosis of mental retardation in infancy is not an easy one to make--indeed the diagnosis of mild mental retardation in the preschool years is often so conjectural that pediatricians, on the whole, prefer to "wait and see." Secondly, there are very few communities which have anything approaching an adequate and comprehensive network of health and welfare services for preschool children. Consequently, many retarded children are not brought forward for medical and psychological assessment until they start school. Thirdly, mental retardation in its milder forms is, more commonly than not, exhibited as a failure on the part of the child to master the rudiments of formal education; it is only when schoolwork becomes intellectually taxing that "slow-learning" children are seen to be falling markedly behind the standards achieved by other children of the same age. Fourthly, in advanced countries, there are more factors operant that increase rather than decrease the incidence of retardation during childhood.

The reasons why surveys carried out at a single point in time always show a decline in numbers with each decade of adult life are, first, inadequate case finding (compulsory schooling provides the one really satisfactory guarantee that few cases will be missed); secondly, the fact that the majority of mildly retarded children, when they leave school, are able to settle as ordinary, if usually somewhat limited, citizens in the ordinary community--that is, they are no longer "mentally retarded"; thirdly, the high death rate among the severely retarded reduces the numbers of gravely handicapped children who survive to adult life.

We know from several surveys that the "peak" prevalence rate for severe mental retardation is found in children and young persons between the ages of 10 and 20 years. In North American and European populations, this peak prevalence is approximately 3.6 or 3.7 per thousand population. There is good reason to believe that this rate approaches the true prevalence rate. Hence, among every ten thousand babies born, there are likely to be between 35 and 40 who will be severely retarded and who will survive at least until their teens.

This finding can be regarded as one of the best documented in psychiatric epidemiology. The administrative consequence is that inasmuch as the numbers of severely retarded children known to the authorities fall short of the predicted rate of 3.6 per thousand, they indicate, in a Western community, the extent of unrecognized needs. Of course, if there is malnutrition, if antenatal and obstetric services are poor, if child care practices and health and welfare services are unsatisfactory, the rates of severe mental retardation are likely to be higher. However, for severe mental retardation (IQ under 50) in childhood, a rate of 3.6 per thousand must be considered a minimal estimate of the true prevalence.

One cannot speak with such confidence about the true prevalence of milder retardation (i.e. the numbers of "educable" retarded children with IQs of about 50-70) because the term is an administrative one which lacks any clear social and biological definition. The term "mild mental retardation" resembles terms such as "poverty" or "social deprivation." There is no doubt that many people are "poor": but poverty in the United States or in the United Kingdom has a different meaning from poverty in, for example, India. It may be mentioned, however, that many educational systems have found that, in practice, between 1 and 2 percent of schoolchildren are too backward to be educated in ordinary classes, and for these children some kind of special schooling is needed. To the extent that special provision within the education system is not made for the numbers of children who are officially recognized to need it, there are again unmet needs.

Are the Numbers Increasing?

The question is often asked whether the numbers of retardates are increasing. We know that because of better medical and welfare services, many handicapped children survive today who would formerly have died. Fears are sometimes felt (though perhaps less often expressed) that because of this, the very size of the problem of mental retardation may become such as to impose an intolerable burden of care upon the rest of society. Fortunately, fears that this may happen are groundless. In a community of 100,000 persons having a crude birth rate of about 18 per 1,000, only 6 to 8 children will be added to the severely handicapped group each year. Even if all of these were to survive until middle age, the total number requiring care would be well within the resources of any modern industrial society, particularly since we know that the majority of even the severely handicapped require very little in the way of basic nursing when they grow up. Moreover, recent evidence has also suggested that the number of congenitally handicapped children born each year is decreasing rather than increasing. It looks as though the factors which have led to a dramatic fall in infant mortality have also greatly reduced the infant morbidity rate: many children who would formerly have grown up mentally or physically handicapped, today grow up as normal, healthy youngsters (Tizard, 1964). However, it seems certain that the numbers of handicapped adults are increasing, simply because handicapped children live longer now than they used to. The implication for services is that we shall have to provide more residential places for handicapped adults in the future, though the numbers of children who require services are not likely to increase proportionately.

A planning authority requires some estimate as to numbers, and sooner or later most planning authorities find it necessary to compile registers of the mentally retarded, and to maintain "waiting lists" for services of various kinds. Sometimes authorities postpone taking any action to improve their services until they have first instituted surveys to ascertain just how many cases they would have to provide for if their services were fully adequate to meet all the demands that might be placed upon them. When this happens, years may pass with nothing done while elaborate surveys of prevalence and needs are carried out. The cost in human terms of such procrastination is incaluculable, and to refuse to begin to meet urgent and manifest human needs until one has "assembled all the facts" is quite unjustifiable. Nevertheless, the facts do need to be assembled.

The Demand for Residential Places

The number of residential places which are required for mentally handicapped persons per thousand of the population is not determined solely by the prevalence of mental retardation. Two other factors are of great importance, namely: (1) the adequacy of the mental health, education and welfare services for the mentally retarded living at home, and for their families, and the amount and quality of residential provision; (2) the attitudes of the public, and of the medical and educational professions in particular, towards mental retardation and residential care (Tizard, 1964). We also know that the demand for residential places is influenced by: the number of places available, and thus the possibility of obtaining one; the quality of residential care, which at present is often so poor that it deters parents from parting with a child who is proving difficult to manage at home; the amount and quality of the community services for retardates living in their own homes (domiciliary services); the age of the child; the age and handicaps of his parents and other members of his family; the aptitude of family physicians, teachers, other professionals, and the general public; the social and economic circumstances of individual families and of the communities in which they live; and finally, the criteria of mental retardation. One cannot, therefore, give a general answer as to the amount of provision which is required.

A Continuum of Services for the Mentally Retarded

Against this background let us consider the services themselves. The President's Panel on Mental Retardation (1962, pp. 14-15) gave an outline of the main needs:

1. Research into the causes of retardation and in methods of care, rehabilitation and learning.

2. Preventive health measures, including (a) a greatly strengthened program of maternal and infant care directed first at the centers of population where prematurity and the rate of "damaged" children are high, (b) protection against such known hazards to pregnancy as radiation and harmful drugs, and (c) extended diagnostic and screening services.

3. Strengthened educational programs generally, and extended and enriched programs of special education, closely coordinated with vocational rehabilitation, specific training and preparation for employment; education for the adult mentally retarded, and workshops geared to their needs.

4. More comprehensive and improved clinical and social services.

5. Improved methods and facilities for care, with emphasis on the home and the development of a wide range of local community facilities.

6. A new legal, as well as social, concept of the retarded.

7. Helping overcome the serious problems of manpower, as they affect the entire field of science and every type of service, through extended programs of recruiting with fellowships, and increased opportunities for graduate students and those preparing for the professions to observe and learn at firsthand about the phenomenon of retardation.

8. Programs of education and information to increase public awareness of the problem of mental retardation.

It will be noted that in this broad statement of objectives, most attention is paid--and rightly so--to services for retarded persons living in their own homes. As a statement of what is required to meet their needs, the "Report to the President" could hardly be bettered. However, it is in regard to residential care that new models are most needed, and the writer believes that in dealing with residential provision, the President's Panel was less farsighted and bold in its recommendations than it was when dealing with nonresidential services. The rest of this paper discusses factors bearing on residential services, and outlines one new model of residential care.

Institutional Care Today

Having considered some of the main factors bearing on the amount of residential provision required, and the part played by residential care in a total pattern of services, let us now look at the type of residential care that is currently provided, and the type that is required.

The usual type of residential care for the mentally retarded, in the United States as well as in most of the rest of the world in which services have been provided, is the large comprehensive hospital, training school, or institution which contains both adults and children on all levels of retardation. In the United States, at least 95 percent of all institutional retardates live in establishments with more than 500 residents (Sheerenberger, 1965). In the past, the justification for the large size and heterogeneity of institution populations was mainly economy. Large institutions were believed to be cheaper to run than smaller ones, and in institutions containing mildly and severely handicapped residents, the less handicapped were able to contribute very substantially to the care of the more handicapped and to the general running of the institution. More recently, smaller institutions and establishments of about 500 beds have been regarded by many authorities as being of optimum size.

The institution of today is also achieving status as a hospital rather than an institution, and progressive authorities are attempting to staff it accordingly. The Technical Planning Committee of the American Association for Mental Deficiency (1964), for example, recommends that a 500-bed institution for the retarded should have "consultant physicians in pediatrics, psychiatry including child psychiatry, electroencephalography, neurology, neurosurgery, orthopedic surgery, physical medicine and rehabilitation, internal medicine, general surgery, anesthesiology, ophthalmology, otorhinolaryngology, radiology, and pathology" who are to make regular visits to the institution and conduct clinics and ward rounds in it. Other personnel and services recommended by the AAMD Technical Planning Committee are on a similarly lavish scale.

Two questions should be asked about a model such as that proposed by the AAMD: Will it provide what is needed? And is it feasible to do so?

It appears to me that the AAMD model of comprehensive, up-to-date hospital-type care has been put forward without sufficient thought having been given either to the role which such an establishment should serve in the general community or to the needs of the residents who will live in it. Remarkably few of the residents in mental deficiency institutions today require hospital treatment; very few even require basic nursing. This latter fact was brought out recently in the Wessex survey (Kushlick, 1967), and in a study in the Birmingham (England) region (Leck, Gordon and McKeown, 1967) investigating the medical needs of all 1652 residents in 13 institutions for the retarded in that region. These residents were similar in most respects to those in England and Wales as a whole. Each resident's requirements were assessed by a hospital physician and the nurse in charge of each ward. In this region, "in which pediatric and psychiatric centers do a considerable amount of investigation which might elsewhere be done in hospitals for the subnormal," there were only seven residents who required investigation or active medical treatment of a kind which would make it necessary for them to be in hospitals. About half (851) were considered to need no medical treatment of any kind. Approximately 40 percent needed "mental nursing," with or without basic nursing (washing, dressing, feeding, etc.). About 13 percent required only basic nursing. The remainder needed no nursing services. "Some of them required simple personal attentions (such as advice concerning washing, dressing, time-keeping, etc.) but most needed only a sheltered environment with opportunities for training and occupation. Nineteen percent of the patients were considered suitable for work outside hospital or in hospital service departments, and approximately 50 percent required therapeutic occupation or vocational rehabilitation." (Leck, Gordon and McKeown, 1967, p. 121).

Similarly, Kushlick (1967) found that in Wessex, about 70 percent of the children in institutions were ambulatory and continent, and almost the same proportion of severely retarded adults were ambulatory, continent, and without severe behavior disorders; 50 percent could feed, wash, and dress themselves without help. A substantial minority of the mildly retarded adults had behavioral disorders requiring primarily social treatment.

While it may be that the findings obtained in these surveys would not be typical of what would be found in other areas, nevertheless the general conclusion is inescapable. Few retardates need hospital treatment; all need education, employment, a satisfying social and cultural environment, and, in the case of retardates who cannot live with their own families, a home in which they can live as normal a life as possible.

In the large institution, it is difficult to provide for these needs. Because of the expense, and because land is simply not available in cities, large long-stay institutions are necessarily placed outside the main centers of population. In consequence, they tend to become isolated from the rest of the community. They are difficult to staff adequately, since they have to provide large numbers of nursing and supervisory staff, and also specialists to deal with possible contingencies; and because they have only tenuous links with other services for retardates and people who live at home, they have to provide for all of the needs of the residents--board and lodging, medical care, education, employment, recreation.

Again, because the institutions are large, they draw residents from a very wide geographical area. Hence, visiting by families is difficult, and contacts between the retardate and his home are weakened and finally lost. It is also difficult to rehabilitate higher functioning residents, many of whom come from urban slums and for whom a period of residence in a sheltered environment in rural surroundings is hardly a good preparation for the city life they will have to live when they return to their own environment.

The question may also be asked whether it is really feasible to attempt to provide a modern hospital-type environment for the retarded on the lines recommended by the American Association on Mental Deficiency. Many, and perhaps most, residential establishments for the retarded fall far short of the standards advocated. On the contrary, they tend to be isolated, overcrowded, understaffed--and cheap to run only because they provide a poor environment. But to bring them to an acceptable standard would require an enormous outlay in cost, and even leaving cost aside, it is doubtful whether it would be possible, even if it were desirable, to provide in every institution however large, the equipment and personnel recommended by the AAMD Technical Planning Committee. Even today, the few specialists that there are in mental retardation (especially physicians and psychologists) spend a disproportionate amount of time dealing with routine problems of institutional retardates, so that they are not able to provide the services needed by retardates who live in their own homes--services which in some instances might help to obviate the need for residential care. If more specialists are centered on institututions, the needs of the rest of the community are likely to suffer still more. Elsewhere, I have attempted to discuss this matter more extensively (Tizard, 1968).

Residential Alternatives to Institutions

Generally, residential institutions were the first form of public provision for the mentally retarded. It is only recently that the problems of retardates who live in their own homes have begun to be studied seriously. Today, as the President's Panel pointed out, it is recognized that an adequate community service should provide, for the retarded who live at home or for their families, good antenatal and obstetric facilities and other preventive services; adequate mental and child welfare clinics; counseling services and practical social help; education; sheltered employment; vocational guidance and training for adults; organized provision, in which voluntary societies and local endeavor participate, for leisure-time activities; etc. The mentally retarded who cannot live in their own homes require these services also; their only additional need is for a home. Thus, it can be argued that the primary job of the residential services is to provide a home; and all the other needs of the retarded should be provided equally for those who live in their own homes and those who have no homes, through the same facilities and personnel.

If we accept these premises, there is much to be learned from studying the organization of residential care for orphans and other dependent children. A great deal of thought has been given to the problems of bringing up dependent children, particularly since the second world war, and there has been much experiment and a careful scrutiny of policy. While institutional policy for the mentally retarded has remained rather static for the best part of this century, that for dependent children in care has changed out of recognition in two decades. The quality of care given to such children far surpasses that which is found in most institutions for the retarded.

In considering what would be the best type of residential provision for the subnormal, one cannot, therefore, fail to be impressed by what has been done for dependent children, the more so as the pattern of care which is favored by those in charge of residential services for children has also been found to be applicable to other groups who may need residential care, notably old people. For just as there has been a turning against the large institutions for children, so large workhouses and institutions for old people are today being replaced by smaller homes.

Following the example of those who have been concerned with the residential care of dependent children, one can envisage an alternative to the large mental deficiency institution in the form of a series of foster homes and small hostels, which would be situated in the centers of the population that they serve. The hostels would be conveniently placed so that the residents would attend the same schools or day training centers as attended by those living in their own homes. The residential centers could also serve as social centers for handicapped persons in the neighborhood. Thus, not only could maximum use be made of the residential facilities, but it would also follow that a retarded person who came to need residential care would not be required to make a complete break with what was familiar to him, while one who was discharged into the community would not have to learn to adjust to a completely new environment.

Some examples of residential services that constitute alternatives to the traditional institutional pattern follow.

Residential provisions for children. Profoundly retarded and perhaps multiply handicapped children might best be placed in a long-stay annex attached to a children's ward or hospital, while the less severely handicapped children capable of attending training centers would be in special residential homes. Alternatively, units for about 15 severely and profoundly retarded children might be established if no hospital annex is available. An example of a homelike residence on which various researches were conducted is the Brooklands model (Lyle, 1959,1960; Tizard, 1964). Yet another form of residential provision is foster care. Efforts to get foster homes for severely or profoundly retarded children have not in the past met with great success, possibly because the social workers making the enquiries have themselves been half-hearted about them. More experience is needed in this area.

Residential provisions for school leavers and young adults. Few mildly retarded adolescent school leavers (drop-outs) and young adults will need residential provisions. Those that do could live in small hostels having between ten and twenty places. Even for this group, foster homes should not be ruled out completely. English experience suggests that it is desirable to have separate hostels for higher functioning retardates who are working out and for lower functioning dependent retardates. The hostels for the mildly retarded should contain both young men and young women. Their function should be to prepare school-leavers and young adults for independent living in ordinary lodgings or in their own homes. At the same time, they should serve as social centers to which other young people living at home could come. Most residents of hostels for the lower functioning would be expected to attend sheltered workshops and similar day services.

Residential provisions for other adults. The number of mentally retarded adults who are of violent or dangerous propensity is exceedingly small. Their special needs can best be met by the same services provided for the care, treatment, and detention of mentally disordered offenders and other mentally disordered persons who are a danger to themselves or the community. The greatest need for residential accommodation for adults is for long-stay homes for the moderately and severely retarded. In the future, these are likely to comprise three-fifths of the total for whom residential care is required. However, very few adult retardates will be grossly handicapped, physically or behaviorally. It is suggested that the needs of these people could best be met in small family-type units separate from but reasonably close to the main sheltered workshops in which many of them would be employed during the day. The hostels could also serve a wider community function as a club and meeting place for other retardates living at home. There is much room for experiment and innovation here.

Costs. The question of costs is one of great importance in the planning of a service. It is also a matter on which it is difficult to generalize from one country to another. Some observations can, however, be made. The main reason why large institutions have been cheap to run has been that they have been grossly understaffed. This applies particularly to the primary care workers and to teachers, youth leaders, and social workers. The question arises whether fewer personnel are required for adequately staffing of large units than of small ones. It is usually assumed that this is so, and that small units are more expensive both to build and to maintain. Recent (unpublished) evidence collected for the Wessex Regional Hospital Board challenges this assumption. To build a new 450-bed hospital could cost 2.5 million British pounds, while building 17 hostels containing the same number of beds would cost 1.3 million, i.e., only about half as much. If a service of adequate quality is provided in our residential establishments, annual running costs are unlikely to be significantly greater in the small units than in the large, and they may even be less. The writer can see no reason why a similar state of affairs might not be found in American conditions, but detailed empirical enquiries would need to be undertaken before realistic estimates could be made about the comparative cost of establishments of different sizes.

General Considerations. There is, in principle, nothing at all novel in any of these proposals, but their implementation would result in a mental deficiency service very different from that which exists in most parts of the world today. It is likely to be very much cheaper than the elaborate alternatives proposed by advocates of modern hospital-type care. Specialist medical and other staffs would be shared with general domiciliary (nonresidential) services. Most of the staff running the hostels would need little nursing training; their training should rather be in child care and development if they are to work in children's units, or in youth work supplemented by some instruction in the special problems of the mentally retarded if they work in adult units. The medical arrangements made for residents who were sick would be the same as those made for retardates living in their own homes in times of sickness. Staff ratios in the proposed units would need to be high enough to cope with minor illnesses as well as the minor physical and social incapacities of the residents.

Conclusion: The Need for Experiment

The case made out for a different kind of residential service is based on earlier studies carried out by the writer and his colleagues and reported in more detail elsewhere (Kushlick, 1966; Tizard, 1968). The main need, however, is for experiment--for planned variation in the pattern of a service which is expanding, and for evaluation of the results obtained from different kinds of administrative practice. The Wessex study, still in progress, is an example of this type of experiment, in that it subjects residential services of various sizes and based on a variety of models to empirical evaluation. The writer believes that it is through such survey and experiment that the greatest advances in our knowledge of how to provide the most effective form of service will come. The opportunities for such experiment are now numerous, and the techniques of social science are sufficiently well-developed for us to be able to make use of them.

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Part V: Toward New Service Models

Chapter 9

Small Special-Purpose Residential Facilities for the Retarded

Lloyd M. Dunn
George Peabody College for Teachers

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SMALL, SPECIAL-PURPOSE RESIDENTIAL FACILITIES FOR THE RETARDED[1]

It seems to me that this is a most propitious time to do something about our residential centers for the retarded. Never before has the climate been better for experimentation with new approaches. Attitudes toward the retarded have improved. Legislators, citizens, the press, and the professions are far more aware of their responsibilities than has been the case previously. Attention to the problems and challenges of retardation has mounted at local, state, and national levels of government. Since a program for national action to combat mental retardation was submitted to President Kennedy by his panel on mental retardation in 1962, each of the states has completed a survey and evolved a state plan of services for the retarded. Today, many local communities are conducting their own studies to devise procedures to fit in with federal and state activities. Thus, the nation appears to be ready to embark on a greater thrust than in the past to provide quality residential services for the retarded. Therefore, it would seem an opportune occasion to explore various options for improving such services, to formulate plans of action, and to implement them. In this regard, my threefold thesis is this:

1. It is my contention that a century of failure of the large, multi-purpose residential facilities for the retarded (as we have known them) is enough; we need now to test the effectiveness of other procedures.

2. Further, it is my belief that we have the knowledge and ability to design and research these alternatives.

3. Still further, it is my hope that the efficacy of small *special-purpose* facilities will be examined as one of the alternatives.

Pros and Cons of Large Multi-Purpose Residential Facilities

The alleged advantages of the large multi-purpose center are well known. Such arguments as the following are included: It is usually the most inexpensive type of facility to operate. It should enable an interdisciplinary, team approach to diagnosis and treatment. It should provide multitracked treatment facility which would enable residents to obtain the most appropriate treatments needed at a particular time. Large multi-purpose facilities should make possible comprehensive research programs. Furthermore, large residential facilities have high visibility for political purposes. Too, over the years, a handful of capable, dedicated professional personnel have devoted their lives to providing residential care to the retarded in such facilities. They have waged a constant fight against political pressures, penny-pinching taxpayers, and an ill-informed public. With such remarkable lack of support, it is a wonder they have been able to make our residential centers as good as they are. These people and their efforts deserve our support.

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[1] The ideational and editorial suggestions of Wolf Wolfensberger are greatfully acknowledged.

The many disadvantages of the large multi-purpose units are equally familiar. In reality, such units have usually tended to be custodial rather than intensive-treatment and rehabilitation oriented. It has long been recognized that institutional living prepares one for residing in such facilities rather than for return to the community. Traditional institutions have been so large that the personalized approach has been sublimated by impersonalized services. Competition and buck-passing among the various professional groups have been known to exist. In most cases, a pecking order among the staff has inevitably evolved to the detriment of the residents. Frequently, they have been operated on the medical model which views mental retardation as a disease, and has an emphasis on labeling and determining etiology; and once one has viewed mental retardation as a disease and affixed the label to an individual, one has a built-in, self-fulfilling prophecy. There has sometimes been emphasis on physical plant, at the expense of adequate staff and services. Too often, there has been exploitation of the more able residents at the expense of their rehabilitation. Furthermore, these large facilities have tended to be segregated from the community, and their staffs isolated professionally. Too, it has been difficult to attract and hold topflight professional personnel. Finally, much of the direct service has been provided by untrained attendants, while the professionals have largely found shelter and status in administrative tasks. Recently, in its "MR 67 Report," the President's Committee on Mental Retardation pointed out that many of our institutions are "plainly a disgrace to the nation and to the states that operate them." In a similar vein, the National Association for Retarded Children recently took the position that "despite much talk and some improvements in recent years, the quality of care of the mentally retarded in state residential institutions remains a national disgrace. There are very few states without back wards which they seldom mention when showing off a new building or a recently-inaugurated special program." Even more recently, Dybwad (1968) charged that the major roadblocks to improved residential care for the retarded are (1) "the medical model which insists on looking upon all institutional residents as patients, regardless of their actual condition," (2) "the view of the mentally retarded as a sub-human species for whom commonly-accepted standards of comfort, decency, and aesthetics need not be observed," and (3) " the power struggles and lack of responsibility to the mentally retarded by the professions who claim to stake in the field."

There are some who would suggest there is so much wrong with our present-day large, multi-purpose residential units that they should be abandoned. Certainly, evidence can be cited that retarded persons who remain in the community make greater progress than those who reside in institutions. As an example, the Cain and Levine study (1963) will be reviewed later in this paper. While I would suggest that we stop expanding or replicating institutions, I would be reticent to advocate their complete abandonment. Instead, we should continue to operate those in existence at least a little longer, with one of their major functions in the next decade being to provide a contrast treatment against which to evaluate other types of residential units. Perhaps with adequate support they can be greatly improved. It may be that research evidence will suggest a continuance of the large multi-purpose facilities for certain, if not for many, retarded individuals, if these units were operated in an optimal fashion.

Alternatives to Large Multi-Purpose Facilities

Because of the grave disadvantages of large multi-purpose facilities, I would recommend that we explore at least two alternative patterns.

One is the small multi-purpose residence. From an examination of the 50 state plans for the retarded it would appear that this approach has high favor today. Generally, the notion is encompassed under the title "comprehensive community center." This arrangement does have a number of merits. It keeps the retarded in their home community. It tends to have a small number of persons in residence. Too, it provides flexibility between day and residential services. However, I am gravely concerned about these proposed comprehensive community centers. For one thing, they tend to favor the larger, urban communities--to the disadvantage of the rural, sparsely populated, and remote areas of our country. But more important, they will fail because sufficient top-flight professional manpower will not be available, in the foreseeable future, to staff them.

When the large multi-purpose residential facilities were initiated, many considered them the last word on the care for the retarded. But now many of us are disillusioned about them, and wonder whether they can succeed even with the most generous of support, since the system has within it the seeds of its own destruction. I predict that a decade or so from now, the advocates of small multi-purpose facilities will be moaning over their failure to make good. Both types of multi-purpose facilities have the same type of major fault. They require a horizontal team with equal, high-level authority, status, training, and responsibility for all the disciplines involved. But from whence are we to recruit these topflight cadres of professionals and how are we to prevent the interdisciplinary rivalry, power struggles, the dissension, the intrigue, and the buck-passing among them? Even a few such centers would tax a regional manpower pool. Thus, I cannot see how a complete range of quality services can be made available in these centers if they are proliferated across the nation, since each would require an array of professions across the different disciplines in order to succeed. In fact, I predict they, too, will degenerate into largely custodial units, staffed--if at all--in large measure by incompetent persons with professional paper credentials.

Some 4 years ago, Hobbs (1964) pointed out the same weakness in comprehensive, community mental health centers, but his warnings were not heeded. Now the staffing crisis is hitting these centers hard. It will be interesting to observe whether we, in mental retardation, are able to profit from the experiences of others, or whether we will fall into the same trap. Failure to recognize the long-term, chronic faults of the interdisciplinary approach, including the debilitating effects on services, is being ostrichlike. Our noble and bold proposals for comprehensive community centers for the retarded in every sizeable community in the nation, if implemented could become--by the year 2000--as sorry a set of facilities as our county workhouses of yesteryear. They could well work to the grave disadvantage of generations of retarded persons. The choice would appear to be between inferior services in small multi-purpose, community centers and superior services in small special-purpose facilities.

It seems to me that the small single-purpose units have much greater opportunity to succeed. However, they may have, in certain cases, the major disadvantage of removing the retarded persons further from their home community than would be the case with multi-purpose community centers. However, when I have faced parents with the hypothetical choice of placing their charge in a more distant center with intensive specialized treatment, in contrast with placement in a local facility with more general services, the choice--in the vast majority of cases--has been for intensive treatment. Too, with modern transportation, travel to even a neighboring state is often not too difficult, and this would only be necessary for very rare and specialized treatments. Furthermore, we are rapidly becoming more and more urbanized as a nation, and thus a major proportion of families will live in densely populated areas that provide an adequate population base for specialized units.

The small special-purpose center has at least four advantages. First, responsibility is clearly assigned to the discipline which provides the specialized treatment. Thus, in a medical treatment center, a physician would be in charge; while in a child development center, a child development expert would have ultimate responsibility, and so forth. Second, it is clear that interdisciplinary power struggles and bickering would be reduced sharply. Third, and very important, the centers would be oriented toward intensive and specialized treatments. Fourth, these small special-purpose units would reduce manpower needs. Instead of basing the operation of top-level horizontal teams of an interdisciplinary nature, these would use vertical teams. At the top of the pyramid would be the highly trained person in the profession, and under him layers of persons who would have gotten, as yet, less training--down to the novice and the technician. The opportunities here for inservice training become immediately apparent.

It is important to note that my bias in favor of the small special-purpose units is based on logic, philosophy, training, and past observations. What is lacking is much empirical evidence to support or refute my convictions. We cannot afford more bandwagons. Thus, my preference now is for carefully controlled comparative studies, wherein the optimal of treatments is provided in all types of residential units. These investigations should be conducted to determine the relative effectiveness of large versus small, and multi-purpose versus special-purpose residence types. The studies need to extend over a long enough period of time to enable us to acquire some solid evidence. At this point, no one type should be taken for granted as superior to the others. We need to find out how good the large multi-purpose facilities can be when adequately financed, staffed, and operated. Clearly, if sufficient quality professional technicians who are specialists in modifying the behavior of the retarded could be found to replace the present attendants, this might revolutionize the larger, present-day units.

It is a testable hypothesis that the small single-purpose facility will pay off best. Should this be the case, we could then begin to phase out our present-day, catch-all facilities, into which we have crowded thousands of retarded persons of all ages, of all degrees of intellect, and with widely varying treatment needs. However, I should like to say again that evidence must be obtained on which to base our actions. It seems to me I have the right to argue my predilections, but I have an equal responsibility to await the evidence before pushing a wide-gauged implementation program. However, I recognize there are those who are opposed to awaiting research evidence before phasing out our present type of facilities. They argue that the efficacy studies will be inconclusive in that all the variables will not be controlled. Furthermore, they take the position that we should go ahead with different patterns even though we lack evidence, since we cannot possibly do worse than we have in the past. Furthermore, we have some evidence--especially from Europe--that small, new units will at least be better than large, entrenched, traditional facilities. As an example, Tizard's Brooklands experiment will be discussed later in this paper.

Another introductory point. As Dybwad (1964) pointed out so well, those who contend that we will eventually be able to do away with residential facilities for the retarded are very probably wrong. In the future, as never before, we will need additional residential facilities. Medical progress has upset nature's law of survival of the fittest, thereby possibly leaving us with more severely retarded cases than in the past. Atomic radiation is modifying human determinance, usually in a deleterious direction. Urbanization, mechanization, and automation are reducing employment opportunities for unskilled laborers, and making society more complex. These factors, along with the great population increase, bring the problem of residential services for retarded persons into new prominence. Too, family disintegration, poverty's lack of adequate medical care, and other social ills are upon us. Thus, instead of needing less residential facilities, I believe that history will bear out my contention that residential units will need to increase rather than decrease in the future. In my view, what will be needed is a greater variety of residences. For example, as Dybwad (1964) has stated: "It stands to reason that so many different types of needs call for a number of clearly differentiated types of residential facilities, of different sizes, with different staffs, different buildings, and different programs." (p. 86)

No matter what type or types of residential facilities we elect for the future, we must do a better job of protecting the retarded person's constitutional rights to proper treatment and care. There have been many malpractices in connection with placement in residential facilities. We need to correct the last vestiges of our degrading commitment procedures, wherein we essentially put away retarded persons in our custodial institutions. We need also to correct our partially closed-door policies which violate the rights of parents and retarded persons to visit together, travel together, and live together whenever possible. There is something to be said for those who recommend wiping clean the legal and residential-care slate, and making a fresh start. There does seem to be a limit to changes which can be made after a century of entrenchment of an organizational structure based largely on the medical model. One advantage of new types of facilities would be that new practices could be initiated which might better preserve the constitutional rights of the retarded individual and his parents. In any event, competitive, alternative approaches should challenge those responsible for the operation of traditional facilities to make needed changes in their practices.

Some Types of Small Single-Purpose Residential Facilities

The second portion of this paper is devoted largely to outlining a few of the small special-purpose residential facilities with which we might experiment. These are intended as examples. The list is far from inclusive. However, they should illustrate the principles for their operation which will first be proposed.

Below are enumerated these seven general principles upon which the units should be based:

1. The profession primarily trained to provide the needed specialized treatment should be in charge of the facility. Thus, a unit which is centered on vocational rehabilitation should be the responsibility of the vocational counselors. Similarly, a center designed to provide a special medical treatment should be the responsibility of physicians, and so on. While the profession providing the central, specialized treatment should be in charge, the other professions should be available in a secondary role when needed, but they must learn to play the role of consultants. Thus the responsibility and the rewards for providing a special-type treatment rest with the profession trained to provide that treatment. This should increase the recognition of both successes and failures. Thus, there should be much less buck-passing. Certainly, we need fewer chiefs and more Indians; professional personnel need to get out from behind their desks and "get their hands dirty." They need to be internally involved, firsthand, in the direct services rather than relying on untrained ward attendants. (In my judgment, over 90 percent of the direct services to retarded residents in our present-day residential facilities are provided by the ward attendant, and less than 10 percent by the physician, psychologist, educator, speech therapist, social worker, vocational counselor, and recreation workers and the other professional groups.)

2. A flexible open-door policy is needed to permit an easy flow, between the community and the centers of professional personnel, of parents, of the public, and especially of the retarded persons themselves. Furthermore, this open-door policy should enable residents to be easily admitted to, discharged from, and returned to the facilities for short periods of time, when necessary. Too, whenever possible, these units need to provide service to retardates residing in the community.

3. The shifting of placement from one special-purpose facility to another should be easily accomplished. Residents should remain at a unit only while the treatment provided is effective and necessary. Anticipated in a continuum of care and treatment would be a variety of placements--dependingon the needs of the residence at a particular time.

4. The number of residents in these special-purpose units should be kept as small as possible. For certain types of

facilities, this would often be from 10 to 50 persons. Seldom if ever would it exceed 100 to 200 residents--even when the treatment is less specialized and intensive.

5. When a number of similar special-purpose facilities are needed in a state, they should be distributed geographically, in keeping with population characteristics, so that the greatest number of residents can be as close to home as possible. For retarded persons who have the potential for employment in industry, the facility should be located near industry. Many would probably do well to be located near universities or other facilities which could provide professional services on a consultative and part-time basis.

6. Consideration should be given to the developments of inter-state and regional facilities in cases of very specialized centers serving relatively rare conditions.

7. Persons should be labeled as mentally retarded and segregated into special units only when essential for a special treatment. Otherwise the label should not be applied, and treatment should be provided from the mainstream of general professional services. Considerably under 1 percent of the general population needs to be so labeled and segregated. I believe that the labeling of 3 percent of the general population as mentally retarded is untenable.

Medical Special-Purpose Facilities. Of crucial importance is both general and specialized medical treatment. High priority should be given to providing every retarded person with optimal service, in its own right, and as a foundation for other treatments. While specialized medical approaches are still few in number, they are increasing rapidly. Thus the need for special-purpose medical facilities is likely to increase sharply in the years ahead. Medical services would appear to be of three types: (1) intensive, short-term medical treatments such as corrective surgery, comprehensive medical study, dental care, dietary or drug control, (2) long-term nursing care for chronic conditions, and (3) general medical care needed by all persons but by retarded persons to a greater extent. Each type of service will be discussed below.

(1) Intensive, short-term treatment. It would be my proposal that short-term, intensive medical treatment be provided at wings, wards, annexes, or institutes attached to medical schools, medical centers, and/or general hospitals, whenever possible. Better still would be to integrate the retarded person into medical facilities in keeping with his specific medical problem. For example, those with an endocrine dysfunction would be placed in a

ward at a hospital or medical center where endocrine problems are studies and treated. This process of integration would remove the likelihood of a person being stigmatized by having a low IQ score and a label of retarded when this is probably irrelevant to his treatment needs. The university-affiliated centers for the retarded--now supported by the federal government--may provide a useful pattern to study. However, another pattern might be small, narrowly specialized medical research and service centers. These might need to be established on an interstate and regional basis. For example, one regional medical center could have a focus on hydrocephalus, while another has a prime focus on a specific biochemical disorder, while still another could specialize in some other clinical condition. There might be a need to draw from several neighboring states to obtain sufficient rare cases. What this approach would do is provide intensive, specialized attention for a person with a particular condition. The limited number of experts available could be centered at these facilities. Of course, placing these specialized medical facilities adjacent to medical centers would likely result in at least some de facto affiliation, even if the facility is under a separate state, county, or city administration.

What are some of the advantages of such a special-purpose facility? Included would be better and more comprehensive medical services than are now generally found in our large residential centers, or are likely to be in comprehensive community centers. Available at a medical school would be a broad range of medical specialists and basic scientists. Such persons as endocrinologists, biochemists, geneticists, and physiologists could be involved in diagnosis and research. The retarded persons would be available to educate medical and nursing students in the care and treatment of the retarded. Thus there would be opportunities for developing more favorable attitudes toward, and knowledge about, the retarded than has been the case in the past on the part of most medical personnel. Physicians and nurses in such settings probably would have better pay, more stimulating conditions of employment, less isolation, more consultation and a greater challenge than would be the case in isolated traditional institutions.

As already indicated, responsibility for the special-purpose, medical programs clearly would rest with the medical and paramedical professions. The type of persons to be served and their treatment would determine whether the prime responsibility should rest with pediatricians, neurologists, neuro-surgeons, etc.

(2) Long-term nursing care. The best method for providing long-term nursing care for the chronic cases is difficult to discern. Whenever possible, the retarded should receive regular nursing home services. This should be especially feasible in the case of senescent retardates in that old age is a great leveler. In terms of

functioning capacity, there will often be little difference between the 85-year old who was a college professor and the one who has been intellectually retarded all of his life. Furthermore, this would enable the aged to be in their home communities.

In the case of chronic bed cases originating in childhood, again the notion of a unit as a part of, or at least adjacent to, a medical center, or college, or at least a general hospital would appear to have merit.

(3) General medical care. Finally, it needs to be pointed out again that retarded persons need good general health services as do all citizens, even more so. These should be available on call at all times, no matter what the type of residential facility in which the retarded is placed. Generally, it is probable that the best such services would be obtained through contracting with physicians in the community, in medical centers, in hospitals, if not in private practices.

The foregoing remarks are intended only to provide a point of departure in thinking through improved medical services for the retarded in a residential setting. Clearly, the medical disciplines with the expertise in this area will need to propose their own patterns.

Nonmedical, Special-Purpose Facilities. Below are a few small special-purpose, nonmedical units which may be worthy of consideration. It is my best estimate that about 90 percent of the present treatment for the retarded, in day and residential settings combined, is nonmedical in nature. Thus, the ratio of nonmedical to medical special units needs to be in the ratio of approximately 9:1.

(4) Child development centers. Child development centers need to be provided for the severely retarded but ambulatory children, with IQ scores approximately 20 to 40, who cannot be served on a day care basis. Such centers might best serve children on a 5-day week schedule, but 7-day services may need to be provided for selected cases. The parents and professionals need to coordinate their efforts so as to foster optimal development of the children. A major goal would be to establish self-care and social skills. In large measure, learning would be programmed on the typical instrumental act paradigm wherein a drive would lead to an appropriate reward through a predetermined, useful instrumental act. Behavior could be shaped in reaching for objects, sitting up, eating, communicating, dressing, walking, opening doors, playing, and so forth. Research to date on the effectiveness of such procedures has led to two conclusions: (1) Even the profoundly retarded can learn much more than we had thought possible, (2) There is little relationship between IQ scores of low-functioning persons and their ability to

learn operant conditioning. The prime advantage of such child development centers would be to move us from our present custodial, defeatist approach for the more severely retarded to treatment-oriented procedures aimed at developing as many independent living skills as possible. The special-purpose units could well be under the direction of experimental psychologists skilled at operant techniques. Of course, other child development specialists would be involved.

(5) Boarding schools. Such schools are needed for a variety of school-aged retarded children. For example, mildly retarded children from rural areas might need such a facility for a 5-day school week. Too, such a facility may prove superior to our current special day classes for moderately retarded children with IQ scores roughly 40 to 60. In this latter case, approximately one-third of the children enrolled might be mongoloid, one-third of them neurologically impaired, and one-third mentally retarded due to rare and/or unknown causes. In the past 20 years, parent groups have mobilized as never before to keep such boys and girls out of our large multi-purpose residential facilities for as long as possible. They have encouraged the establishment of special day schools and classes in local communities, but these have not worked well for a number of reasons, including the shortness of the treatment, which usually extends for only 3 or 4 hours a day of actual instruction, at the most, and for only 180 days a year. Soviet special educators, in learning of our special day schools and classes, have observed that only through boarding schools which operate around the clock and calendar with both school and after-school instructors are the children likely to develop adequately.

There is some evidence that neither our school programs in large residential facilities nor our community special classes are working very well. For example, Cain and Levine (1963) have compared the relative effectiveness of four types of treatment for the trainable mentally retarded. One group lived on the wards of a large residential facility. The second and similarly institutionalized group attended the school at the institution. The third group lived in the community and attended special day classes. The fourth group also lived in the community, but remained at home with their parents without receiving any special education services. Four major findings of this study were as follows. First, both special day class children and children remaining at home made better progress in social competence than their counterparts in residential facilities. Second, special day class training, as presently constituted, was no more effective than the informal training provided when the child remained at home. Third, both those of the wards and those attending school at the large residential facility decreased in social competence; apparently attending school in a residential facility is not sufficient to overcome the negative effects of institutionalization. Fourth, great variability existed in the special day class training programs; a few teachers provided a sequential, meaningful curriculum which proved quite effective, while many others were primarily providing day-care, baby-sitting, and recreation services.

The Brookland's experiment conducted by Tizard (1962) in England provides evidence in support of the small boarding school. He and his associates compared two groups of trainable mentally retarded children, one in a large multi-purpose institution, the other in a small home-like boarding school located on a small estate and under the direction of kindergarten teachers and child development personnel. The small boarding school proved significantly superior for the children.

These two studies, when viewed together, suggest the need for small boarding schools for the moderately retarded. While such units would provide boarding facilities on a permanent basis for a few children, much more frequently the children would be boarded at the facility only through the workweek, returning to their homes on weekends. Further, these centers would provide day facilities for some children who would be brought to them in the morning and picked up again in the evening by the parents. Thus a combined community and residential facility is proposed. Such units should be the professional responsibility of kindergarten teachers and/or special educators, if not a new professional group which might be labeled child developmentalists.

(6) Rehabilitation centers. A variety of different types of rehabilitation centers are suggested for young adults in their teens and twenties who are referred to residential facilities for the first time because society or the home can no longer tolerate their behavior. These young adults of usually moderate retardation and borderline intelligence will have exhibited management problems such as delinquent acts and promiscuous sex behavior, or will lack saleable or social skills to enable them to exist in our increasingly complex and difficult society. My suggestion would be that most of these young people are rehabilitation problems. Therefore we should turn to vocational counselors, clinical and counseling psychologists, and group social workers to rehabilitate them. These professions need to design, foster, and operate a series of rehabilitation centers, with different foci, for these teenagers and young adults. It would seem desirable that the size of such facilities be quite small, perhaps numbering, at one time, no more than 10 to 50 residents. Services at such units would center on rehabilitation, counseling, sheltered work, teaching vocational skills, providing a home, structuring behavior, and providing a temporary haven in times of community and home crisis. Thus, these special facilities need to have minimum flexibility. They need to provide a boarding facility

for persons in residence--both for those who are full-time residents, and for those who live at the facility and have secured competitive community employment but are not ready for complete independence. Too, they need to provide shelter, on a day-to-day basis, for persons who may have been at the facility some time in the past and are returning to mobilize their potentials so as to return to society. In this regard, they need to function in many respects like our old half-way houses. Furthermore, some of them need to give service to members of the community who spend their days at the facility for protective purposes and for learning vocational skills while living at home. Certainly the key to the success of such facilities would be an "open-door policy," if rehabilitation is to have meaning.

(7) Hostels. Such residences are suggested for retarded adults who have no home and whose primary problems are not medical. These persons will usually be in the moderately retarded to borderline intelligence range, with chronological ages extending from young adulthood to senescence.

These hostels would emphasize self-care, economic productivity, recreation, effective use of leisure time, and socialization. Here professional responsibility would rest primarily with group social workers, though other group specialists might be considered. The idea would be to develop small special-purpose facilities on the cottage plan, as has been done for years in certain European countries. It may be that these individual cottages would serve as few as 6 to 12 persons. They might well be located in small towns, as has been the case in many of the Lowland Countries in Europe where the community or village is dedicated to the care and welfare of the retarded adults as a community enterprise. Such facilities probably should be on spacious grounds with the central buildings providing sheltered workshops as well as dining and recreational facilities. Community physicians and hospitals would provide the needed health services.

Concluding Comment

It has been my plea that the virtues of small special-purpose residences be considered carefully in contrast to small multi-purpose community centers and large traditional multi-purpose institutions. Clearly a wide array of residential services will need to be devised if retarded persons are to have quality care and treatment now and in the future. The exciting thing is that society appears ready to try out different patterns of services, shaped to the emerging social order, so that we can begin to correct our inexcusable errors of the past.

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Part VI: Model Service Models

Chapter 10

A Metropolitan Area in Denmark: Copenhagen

Niels E. Bank-Mikkelsen
Danish National Service for the Mentally Retarded

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A METROPOLITAN AREA IN DENMARK: COPENHAGEN

As a model I have chosen the service system in the area of Copenhagen, which forms a regional unit of the Danish National Service for the Mentally Retarded. Before describing this regional system, I will discuss the larger background of services in Denmark.

Brief History of the Development of Service Systems in Denmark

Denmark covers some 43,000 square kilometers (16,538 square miles) and has a population of 4.8 million. Copenhagen, the capital of Denmark, lies on Zealand, the largest of the Danish islands (7,543 square kilometers; 2,901 square miles) and has just over one million inhabitants. Denmark has a highly developed communication system and a relatively even distribution of social, medical, and educational services within easy reach of the citizens.

In 1855 and 1865, the first two institutions for the mentally retarded were established by private organizations. Between 1890 and 1922, social security programs initiated earlier were supplemented with more general social insurance acts of parliament, covering old-age benefits, health insurance, industrial injuries, disability insurance, relief, and unemployment. The costs of these programs are divided between the national government, the local authorities, and the citizens as members of the insurance system. Social security schemes are to a large degree financed through general taxation.

The National Assistance Act of 1933 defined institutional care, treatment, education, foster-home care, etc. as the responsibility of the Danish Government. By this social reform legislation social programs of the 19th and early 20th century were consolidated. This act was reaffirmed and updated by the passage of the National Assistance Act in 1961, and supplemented by special acts on the deaf, the blind, and the mentally retarded (the latter in 1959). All those not covered under the provisions of any of the acts are eligible for services under the Rehabilitation Act of 1960.

In 1937 an act to combat sickness and mortality among infants in their first year was passed as the first of a series of laws concerned with preventive medicine. A Maternity Welfare Act, in force since 1945, provides for free regular examinations of all expectant mothers by a doctor and a midwife, and the health of children is regularly checked in their homes by visiting public health nurses. In 1946 an act was passed which provides for nine free preventive medical examinations of infants from birth to their seventh year. At this age, health control is taken over, under the act of 1946, by the school physician attached to each school, who carries out regular examinations. Any departure from normal development is brought to the attention of the family physician, who provides for the required treatment. Preventive work is also the responsibility of the general practitioner, who plays a very important role, although municipal clinics have been set up for this work in Copenhagen and some of the larger provincial cities. Everyone may freely choose where he wishes to be examined.

Social research, including studies of the conditions of handicapped persons, is carried out by the Danish National Institute of Social Research.

A commission (the Social Reform Commission) appointed by the government in 1964 has been charged with preparing and reporting on a total reform of the organizational, administrative, and financial structure of the Danish social security system.

The Obligations of the Danish Service System to the Mentally Retarded as Defined in the Act of 1959

The act concerning the care of mentally retarded and other handicapped persons grants the mentally retarded civil rights in nearly all respects. With this act,[1] the Mental Retardation Service[2] has been established as a semi-independent organization under the jurisdiction of the Ministry of Social Affairs.

The service system for the mentally retarded is divided into 12 regions as will be seen from the attached sketch, each region being administered from a center. However, a single superregional training program for care personnel is operated in Copenhagen, as described in the appendix.

The entire organization is governed by a board of directors, acting in concert with the regional centers. The board of directors consists of eight members appointed by the Minister of Social Affairs. One members is to be a representative of the National Health Service, one is to represent the Ministry of Education, and one is to be a representative of the countrywide association of parents for the retarded. The remaining five members are persons who must be expected to have insight and interest in the Mental Retardation Service. This composition is characteristic of the multidisciplinary feature of the Service. The members are appointed for 4 years--a period that

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[1] A copy of the 1959 act is found in the Appendix.

[2] The reader should keep in mind that there are two "Services:" the National Health Service, and the Danish Service for the Mentally Retarded.

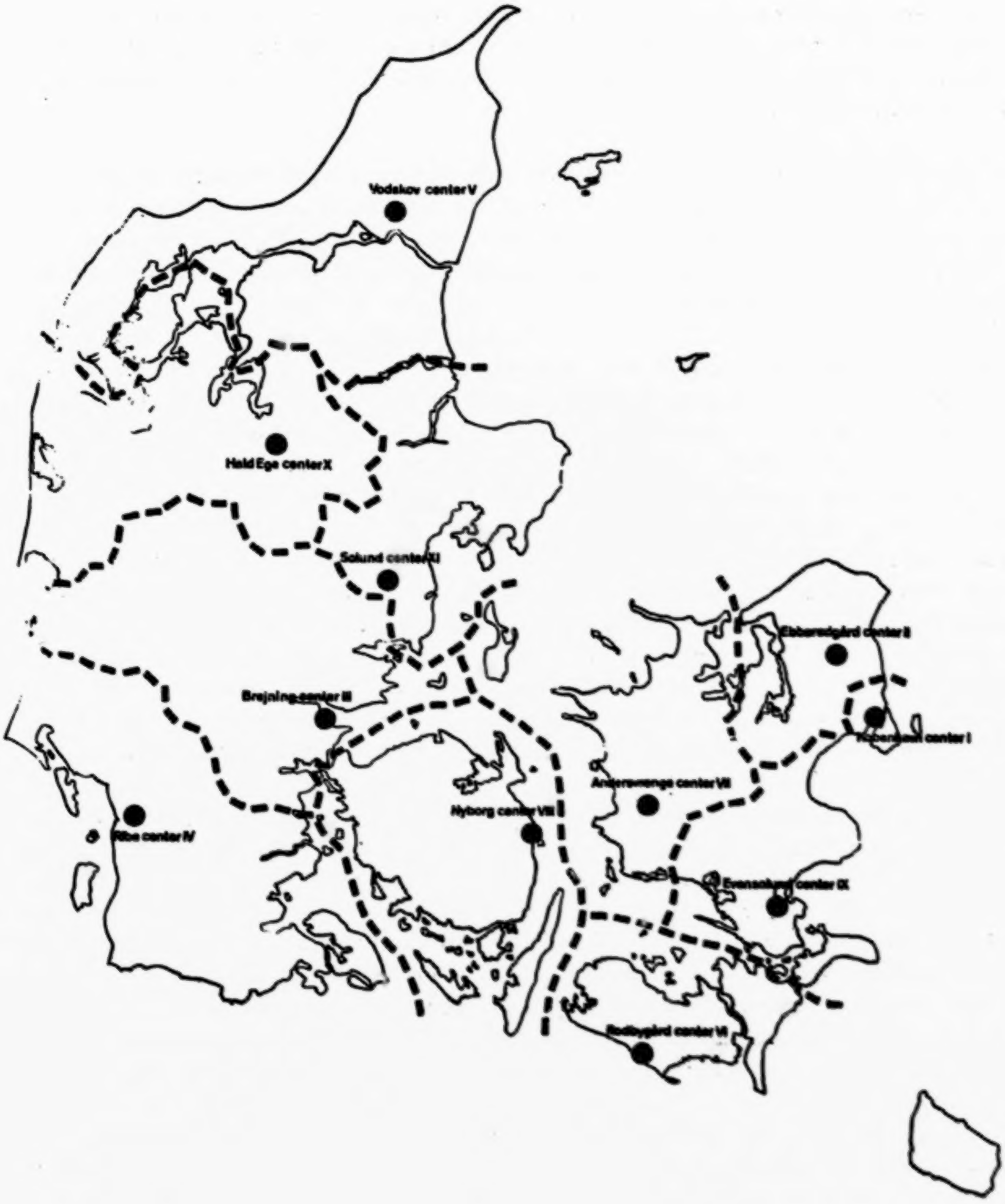
Vodskov center V
Hald Ege center X
Solund center XI
Brejning center III
Ribe center IV
Nyborg center VIII
Andersvænge center VII
Ebberødgård center II
København center I
Evenschgård center IX
Rødbygård center VI

Figure 1: Map of Denmark and Mental Retardation Service Regions

corresponds to the electoral period of local councils. The board is chaired by the Director of the Service, who is appointed by the King.

It is the duty of the board of directors to administer the act, to observe development within the field, and to advance to the Minister of Social Affairs proposals as to measures consistent with new developments. The Minister of Social Affairs takes care of the establishment of regional service centers, and other means needed at any time to attain program targets.

For each regional center, a board of control is appointed to control the functions of the center and to administer jointly with the local regional management the residential services within the region. This board consists of five members, one being a representative of the parent's association.

Entitled to receive help and assistance from the Service are those who are or appear to be mentally retarded and who also appear to be in need of special services. Request for assistance, or termination of assistance, can be advanced by the person in question or by other persons or authorities on whom the responsibility rests to attend to the affairs of the person in question. Should the authorities within the Service learn by other means about any person who may be considered in need of services, they should bring about the necessary investigations to verify whether assistance should be given and, if necessary, arrange for initiation of such assistance. Public authorities, physicians, teachers, etc., who through their activities are in touch with the mentally retarded or other handicapped persons, are expected to furnish reports to the Service.

The service is required to give guidance to parents on the care, treatment, etc., of their mentally retarded children, and on existing facilities for help and assistance.

A child who is functioning in a retarded fashion and who can follow neither the ordinary primary school education nor the special educational system for slow children is subject to compulsory education and training from the age of 7 to the age of 21. This school obligation may be fulfilled in any number of ways, including home-tutoring.

As regards children and young people under 18 years of age and handicapped people under care beyond this age, services against the wish of their parents may be imposed only with the consent of the child welfare authorities.

There are detailed review and appeal procedures before services can be imposed upon individuals contrary to their own wishes or the wishes of those responsible for them.

Decisions as to the initiation or termination of relief measures against the wish of a person over the age of 18 are to be brought before a Central Tribunal set up by the Minister of Social Affairs, consisting of a chairman, a social worker, and an expert in psychiatry. The tribunal shall settle the question as soon as possible and within 1 month after receipt of the appeal. The settlements of the Central Tribunal can, within 1 month, be appealed to the Court of settlement in accordance with the rules laid down in the Administration of Justice Act. The request for submission to the court may be forwarded by the person in question or by a person who acts on his behalf. If the Central Tribunal has passed a decision, the person who has appealed the case must be informed and apprised of his right to request that the case be submitted to the court.

In cases where relief measures have been initiated or terminated, the Service may advise the probate court accordingly in order to have a qualified and willing guardian appointed, who has to keep himself informed of the conditions of the mentally retarded person and who sees to it that relief measures are not upheld for a longer period than necessary.

The Service is entirely financed by the national government. It is responsible for services to citizens, from the cradle to the grave if necessary, and it counts among its retarded clientele groups of blind, deaf, motor-handicapped, epileptic, brain-injured, psychotic, emotionally and behaviorally disturbed, and language-handicapped persons.

All mentally retarded persons receiving some kind of help are registered at both regional and national registers. This registration is linked up with the registration of the whole population which is being prepared in Denmark, by which all persons, including the mentally retarded, are given an identification number.

By means of electronic data processing, the registration provides up-to-date information on all clients and collects material for statistics and research activities in the areas of treatment, planning administration, and client training. Also, the system will disclose personnel needs and will be of great value for comparative studies on an international level.

At first, the registration comprises only name, birth date, address, the form of services rendered, and data concerning the family of the client. Any admissions, changes in service measures, regional movements, discharges, etc., will be registered in a uniform way and will be entered into computer storage which writes out the necessary cards for the national and regional registers. It is contemplated to extend the range of data with medical, educational, and social inquiries in order to get a more comprehensive picture of our clients, their needs, and the services that are given. The basic inquiries are being delivered by the regional centers at rather short intervals and go through the headquarters to the computer center in charge of the registration, while the output is going the other way, namely from the computer center to the headquarters and back to the regional center. The computer center thus provides all mental retardation regions with registers, statistics, etc., on a regional and national basis.

Current Implementation of the Act

The Danish Mental Retardation Service is a system which aims at securing the highest possible attention to the unique variety and individuality of the clientele. Being confronted with a developmental continuum covering an IQ range from approximately 0 to 75 and a total life continuum, our Service is forced to have a very high degree of differentiation in terms of residential facilities and professional disciplines involved in a comprehensive care system. No other establishment charged with an educational responsibility has to cover such an extensive field as the Danish National Service for the the Mentally Retarded. Accordingly, there is a high degree of differentiation of agencies, as will appear from the enclosed organizational chart (see Fig. 2).

The purpose of a modern service for the mentally retarded is to "normalize" their lives. For children, normalization means living in their natural surroundings, playing, going to kindergartens and schools, etc. Adults must have the right to leave the home of their parents, to be trained and taught, and to pursue employment. Children as well as adults need leisure time and recreation as part of a normal life. We are trying to integrate the retarded into the community in the best possible way. We help them in making use of their abilities, no matter how limited these may be. The mentally retarded have, along with other human beings, a basic right to receive the most adequate treatment, training, and rehabilitation available, and to be approached in an ethical fashion.

To provide the retarded with normal life conditions does not mean that we are oblivious of our duties to offer special care and support. We simply accept them as they are, with their handicaps, and teach them to live with their handicaps. Whatever services and facilities are open to all other citizens must, in principle, also be available to the mentally retarded.

One function of residential services is to provide relief of acute disturbances in the family situation for a client living at home. Severe illness, divorce, etc., may often indicate that a

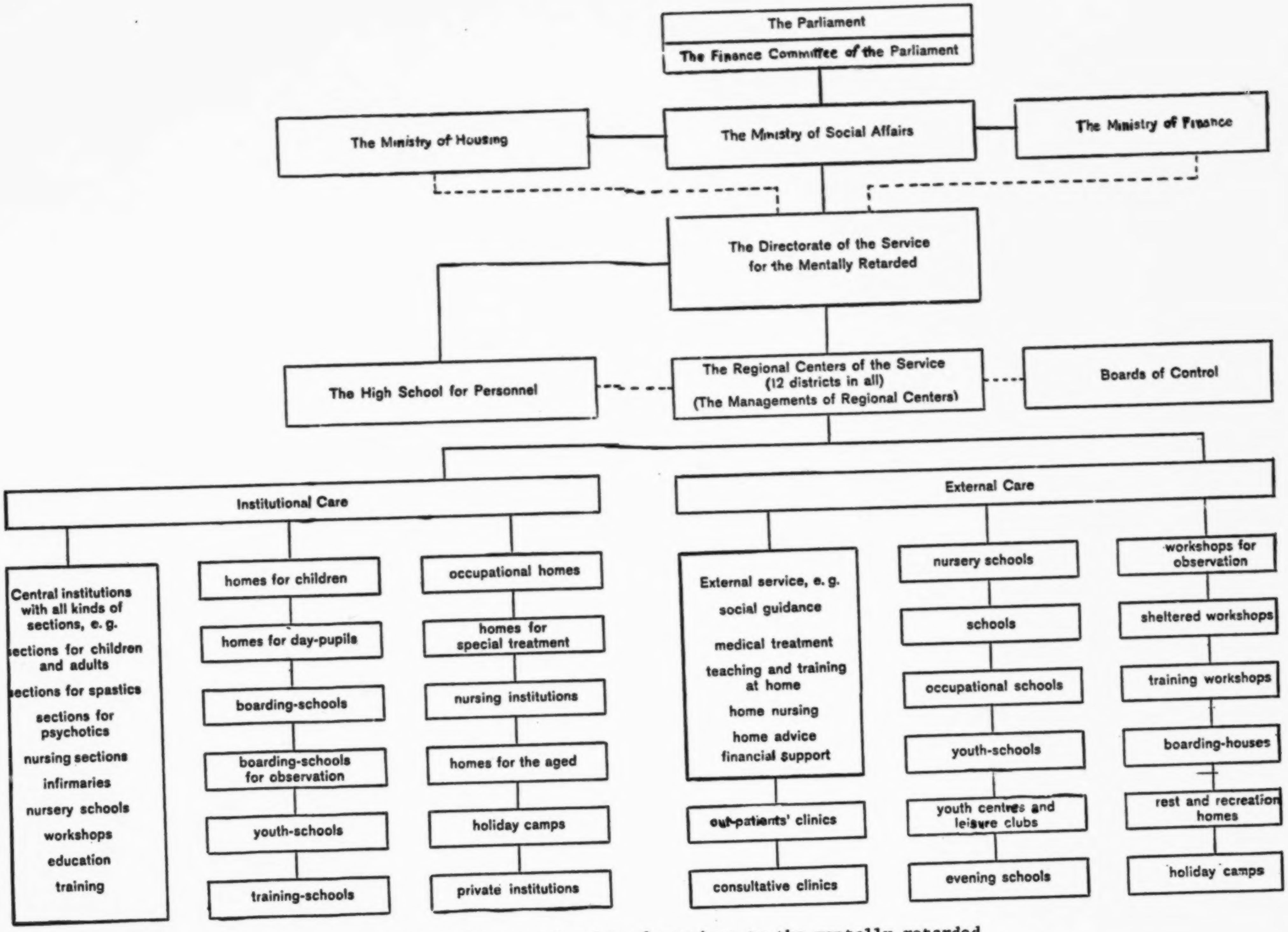
The Parliament
The Finance Committee of the Parliament
The Ministry of Housing
The Ministry of Social Affairs
The Ministry of Finance
The Directorate of the Service for the Mentally Retarded
The High School for Personnel
The Regional Centers of the Service (12 districts in all) (The Managements of Regional Centers)
Boards of Control
Institutional Care
External Care
Central institutions with all kinds of sections, e. g.
ections for children and adults
ections for spastics
sections for psychotics
nursing sections
infirmaries
nursery schools
workshops
education
training
homes for children
homes for day-pupils
boarding-schools
boarding-schools for observation
youth-schools
training-schools
occupational homes
homes for special treatment
nursing institutions
homes for the aged
holiday camps
private institutions
External service, e. g.
social guidance
medical treatment
teaching and training at home
home nursing
home advice
financial support
out-patients' clinics
consultative clinics
nursery schools
schools
occupational schools
youth-schools
youth centres and leisure clubs
evening schools
workshops for observation
sheltered workshops
training workshops
boarding-houses
rest and recreation homes
holiday camps

Figure 2: The organization of services to the mentally retarded

child would benefit from a short-term stay outside his home. It is preferred in such cases not to use the larger institutions but rather a small-size house with no more than 10-20 places and a very warm and intimate atmosphere; here, the mentally retarded child may reside for up to 3 months.

However, to help parents to keep their child at home we offer different forms of assistance, such as counseling in child care and management, and/or financial aid, if necessary. Since it may often be difficult for parents and relatives to have a mentally retarded child at home throughout the whole day, we offer day nurseries, creches, kindergartens or, if these are not available, help in the form of home treatment, education, and training of the child, including physical treatment such as physiotherapy.

To provide parents with leisure time and free evenings we offer babysitting, often by qualified babysitters who know what mental retardation is. At the very least we try to provide such a service to families with a severely retarded child. During parents' illness--as a rule a great problem when a mother is ill--there is a possibility of providing homemaker service, i.e., assistance by a specially trained person who takes care of the housewifely duties, including the care of children. We offer weekend stays in kindergartens and similar agencies for the care of children from Saturday to Monday morning.

The mentally retarded of all ages, whether they live at home or in residential facilities, are entitled to recreation in recreation centers, holiday camps, etc. Holiday trips to foreign countries are frequently carried out, especially for those living in residential facilities.

Depending on their conditions, adults live in small homelike environments if treatment in a hospital is not required. Hostels and the like have proved to be a brilliant solution, especially for those who are working in open employment or in sheltered workshops. Hostels of the Danish system take normally a maximum of 20 retarded residents. There are rest homes for those who need care; for the older ones, there are homes for the aged.

Current trends and thought are such that we can expect in the future that children, mainly of mild retardation, will live in small children's homes (school-homes); in units for no more than 8 children (boys and girls mixed) per house; and in single or double rooms. We expect that such children will attend the nearest school operated by the Service on equal terms with retarded children living in their own homes. Also, considerable effort is made to serve children and adults in separate facilities.

Current residential provisions in the Copenhagen area include one boarding school. This type of residential provision was formerly considered necessary for geographical reasons, as it still is in countries with a widely scattered population and poor communication. However, it is clear that in Denmark, the rationale for school-homes will change in emphasis from geographical to social and behavioral considerations.

Other current trends are toward a reduction of residential plans as rehabilitative services are emphasized. We believe that a comprehensive system of day-care centers, especially for the moderately retarded, can reduce the need for residential services. As a consequence, we expect to observe in years to come a change of the residential clientele toward more severe and complicated cases.

Regional Centers

As mentioned earlier, there are 12 regional service units in Denmark. Each regional center is administered by a four-man team: an administrator, a chief physician, a director of social work, and a director of education. This team is jointly responsible to the (national) board of directors for all activities within its region. The Copenhagen region is somewhat atypical in having two such teams, one for the children's service and one for the adult services.

The multidisciplinary feature is of inestimable importance for a purposeful treatment of clients with multiple handicaps. The cooperation between the different disciplines of the treatment team has been beyond expectation, both in residential and nonresidential services. Medical care, including psychiatric treatment, plays a decisive part, even if the sole purpose of day services may seem to be of socio-pedagogical nature. Schools operated by the Service, for example, provide for medical treatment and social guidance to an extent which is unknown to ordinary schools.

The primary task of an administrator in the field of mental retardation may be the organization of public-relations activities in order to focus the attention of influential groups within the government and the population on the obvious ethical obligations towards the weakest in the community.

The Copenhagen Region

Regional Center I (for the Copenhagen area) is subdivided into a center for children and a center for adults. The headquarters of the Copenhagen Children Center is the Children's Hospital at Vangede, and that of the Adult Center is the Center Institution Lillemosegard. Both Centers receive their clientele from Copenhagen and its suburbs and from the adjacent island of Bornholm.

The Children's Service

The center for services to retarded children of Region I is located at Children's Hospital in Vangede. Inaugurated in September 1966, it is the result of 10 years of planning. This planning was inspired by the work of the committee which prepared the act of June 1959, concerning the care of the mentally retarded.

The construction of the hospital was finished in 1965, and the costs amounted to Dan.Kr. 29,250,000[3] ($3,900,000;/$7,800,000), that is 90,000 Dan.Kr. ($12,000;/$24,000) per child. The cost per year per child is approximately 52,000 Dan.Kr. ($6,933;/$13,867). By way of comparison it may be mentioned that the cost per child in an old institution in the province of Jutland amounts to Dan.Kr. 23,000 per year ($3,067;/$6,133), and in another institution on the island of Funen, Dan.Kr. 40,000 ($5,333;/$10,677) a year.

The Vangede center administers intramural and extramural services. The intramural residential facilities include the following: main building with outpatient clinic and the regional center offices, residences, lecture rooms, canteen, assembly hall, clinic building with special equipment, building for physiotherapy, living units for children with acute illness, units for cerebral palsied children, units for children with severe motor handicaps, units for special observation, units for children with moderate or profound retardation, units for psychotic children, and schoolrooms for education and training.

These facilities serve 325 moderately, severely, and profoundly retarded children suffering from the most varied disorders and complications. The needs of these children and their families are such that their homes cannot cope with the problems. Areas of attention, based upon pediatric, ortho-psychiatric, and clinical psychological diagnosis are simple mental retardation, brain damage, hearing loss, visual loss, specific behavioral and emotional deviance, motor handicap, dysphasia, speech disorders, and multiple handicaps. Included in the number of 325 are about 35 children who live at home and who are served in the daily treatment and educational programs of the hospital.

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[3] At official rates of exchange, there are 7.5 Danish Kroner (Dan.Kr.) to the dollar. However, it is estimated that the purchasing power of the dollar is closer to 3.75 Dan.Kr. Therefore, in all subsequent discussions of costs, both official exchange and estimated purchase values will be given.

Vangede is an open, friendly children's community. The buildings are small houses, spread out on the ground, all one story high so that the children have direct access to playgrounds and lawns. The high tiled roofs contribute to the general impression of a children's village.

The many living units for relatively mobile children have been the model for all other living units, and much trouble has been taken to create a friendly and homelike atmosphere. There are no dormitories which have to be closed during the day, but rooms for one, two, or four children in which each child has his own corner of the world, with a bed, a closet, a wall board for his pictures and drawings, and a small bureau for his toys and things, whether valuable or quite simple. There are 15 children in each house, and boys and girls, and younger and older children, are mixed.

Some living units for children suffering from motor handicaps must be of a more hospitallike character. Thus, the buildings for spastics are provided with broad halls and much space to accommodate wheelchairs and walking instruments. Houses for severely handicapped children (most of whom are confined to bed) have rooms (each room with its own bathroom) which have five beds and which open directly out on the play and living area. Children get out of the bedroom during daytime for activities in the living room or, in summer time, in the open air.

A building for physiotherapy provides ample space for individual or group treatment, and there are special classrooms for education and speech lessons. Walking exercises supported by water can be conducted in a training swimming pool, and patients with athetotis can relax in the lukewarm water. Psychotic children may enjoy playing together in the water. Big and small children can be supported from the edge of the pool, the floor being adjustable to various depths.

One building includes clinical facilities for the dentist, the ophthalmologist, and the otologist whose technical equipment the speech-therapist utilizes. There is an electroencephalographic laboratory and X-ray apparatus for pneumoencephalography. An operating room is fully equipped with all modern technical facilities. There is a laboratory for routine procedures as well as for scientific research. It is considered most important for the children's feeling of security that examinations and treatment can be made within the hospital in its own milieu and not in strange hospitals and clinics.

The main building, situated at the entrance of the hospital, houses staff offices, administration, and outpatient services. This building serves the hospital and is the starting point for the entire work of the children's department of this regional center.

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Around the basic core of the small children's homes is offered an educational program which consists of 6 kindergartens of 10 children each with two teachers (male and female) in each group, supplemented by activities in modeling and ceramics, papercraft, woodcraft, metalcraft, textilecraft with printing and sewing, rhythmics, dramatics, and a Robinson (i.e., adventure-oriented) playground.

The educational staff consists of 45 teachers under the supervision of a headmaster. Special teachers are available to provide for individual or small group programs, and for children with specific learning disabilities and/or emotional behavior disturbances. The didactic objective is the "pedagogy of the obvious," based upon a balanced challenge, considering personality as a function of a sequence of learning processes. This approach is more comprehensive than any previously attempted in Denmark. The educational activities in the Children's Hospital, as an integrated part of the total care system of the Children's center, are considered an educational obligation of great dimensions.

Social caseworkers, child psychiatrists, pediatricians, psychologists, educators, nurses, etc., meet every week in the conference rooms. This exchange of experiences and professional knowledge is influencing the attitude of a whole staff toward the children and the problems met with. This weekly conference is considered a decisive factor in the working method of the center.

In addition to intramural services, the center administers the following extramural facilities: 8 kindergartens, 3 training schools for moderately retarded children, 4 schools for mildly retarded children, 1 special treatment home, and 1 residential boarding school.

The children's service staff consists of about 540 persons, of which about 300 work in the intramural services and 240 in the extramural ones. This staff consists of 11 physicians, 10 physiotherapists, 71 educators, 39 administrative personnel, 247 care personnel, 13 social workers, 133 kindergarten teachers and similar personnel, and 16 gardeners, domestic workers, etc. In addition, there are part-time and consultant specialists.

The standards of the Copenhagen Regional Center for both children and adults are steadily evolving. This means that the above-mentioned figures are by no means to be considered as meeting all the actual needs for personnel within this region.

Children's Hospital is only 880 yards from Lillemosegard, which is the institution where the adult center is located. Both facilities are served by a common kitchen, heating plant, and mortuary at Lillemosegard. The clients from the Children's Hospital are transferred to Lillemosegard at an age of 15 years, or when they have finished school, but not later than their twenty-first year. The staff of both institutions are working in close cooperation.

The Adult Service

Lillemosegard is the center institution for adult services for Region I (Copenhagen, its suburbs, and the island of Bornholm). Lillemosegard is an old institution for approximately 300 adult residents which was modernized and remodeled in the beginning of this decade. This modernization was completed in 1964; the costs for remodeling amounted to 22 million Dan.Kr. ($2,933,333;/$5,866,667), that is 73,000 Dan.Kr. ($9,733;/$19,467) per resident. Maintenance cost per year per resident amounts to nearly 27,000 Dan.Kr. ($3,600;/ $7,200).

Lillemosegard is hospital, employer, and home for moderately, severely, and profoundly retarded adult men and women who are in continuous need of medical and nursing care. It is the headquarters of all services for retarded adults within Region I. The center institution is comprised of residences, infirmary, administration buildings, central heating kitchen, medical administration unit, inspector's house, central heating installation and boilerman's house, assembly hall and canteen, physical medicine unit, units for occupational therapy and schools, dwelling departments for the staff, mortuary, and workshops.

The old buildings, which had been erected long before the more recent extension was started, have been changed into departments for occupational therapy, sheltered workshops, classrooms, etc. The new buildings are mostly one-story high.

There are 14 intramural residential units. None of these have dormitories; instead, they have rooms for one, two, or three adults, who are all allowed to have furniture of their own, and who all have a key to lock their cupboards and drawers.

Hospitallike wards are available for shorter observation periods and for treatment by a psychiatrist. Wards for cerebral palsied adults are provided for the physiotherapeutic treatment of motor handicaps.

Meals are served in dining rooms at small tables, and clients spend their leisure time in intimate living rooms or, if desired, in the hobby rooms after hours. Those whose condition may call for more individualized occupation normally use the hobby rooms during daytime for occupational activities.

During the day, the clients of 13 residential units are occupied with different activities, mostly with work in the sheltered workshops or the garden. More impaired residents living in larger units are treated on their own wards by occupational therapists.

The care system of the center provides for a high degree of individual education, even though the residents are adults; for long range planning of treatment, care, vocational training, and education; as well as for equal rights and opportunities for services for persons with all degrees of developmental handicap, no matter how severe these might be.

The educational facilities such as workshops and schools are in the center of the "village." A staff of specially trained teachers take care of the educational activities under the supervision of the director of education, who is one of the four members of the administrative team. Special teachers provide individual or small group programs for a maximum of six adults with similar learning disabilities and/or behavioral disturbances.

The staff at the workshops consists of skilled workers and/or care personnel, and the recreation centers employ specially trained personnel. The workshops provide for a differentiated occupational program, which, among other things, includes industrial production, ceramics, carpet weaving, musical instruments, woodcraft, textile-craft, and metalcraft.

Beyond the center institution we have in the Copenhagen area advisory clinics and counseling services, 4 relief homes, 8 sheltered workshops for a differentiated clientele and various types of work, 5 hostels, and 1 foster home. The number of additional extramural facilities is rapidly increasing.

The adult service has a staff of about 380 for intramural service and 150 for extramural services. In addition to part-time and consultant specialists, the total staff of 530 of both the extramural and intramural facilities consists of 7 medical doctors, 15 educators, 10 physiotherapists and occupational therapists, 38 administrative personnel, 190 nursing personnel, 19 gardners, domestic workers, etc., 195 unskilled workers and aides, 16 social workers, and 40 skilled workers.

Children's Hospital and the reorganized center institution Lillemosegard are the first modern residential facilities in the city of Copenhagen. In former days, all institutions for mentally retarded clients were located at remote places, which accounts for the fact that there were relatively few facilities in the city of Copenhagen. However, the most interesting feature in the development of mental retardation facilities is probably an increasing number of small day residences and hostels--or group homes--so that center institutions are merely a part of a highly differentiated service organization with various other types of help and assistance to our clientele.

Costs

The total costs for the Danish Service for the Mentally Retarded in the fiscal year of 1966/67 amounted to nearly 350 million Dan.Kr. ($46,666,667;/$93,333,333). Beyond that amount, approximately 7 million U.S. dollars (purchasing power about 14 million U.S. dollars) is annually used for building activities. These costs must certainly rise to twice the afore-mentioned amount before the standard of our system is about as good as we would like it to be.

The annual expenses of the Copenhagen Center for Children, including external facilities, amount to 24.7 million Dan.Kr. ($3,293,333;/$6,586,667). The annual expenses of the adult center amount to 20.2 million Dan.Kr. ($2,693,333;/$5,386,667).

Planning for the Future in the Copenhagen Region

Some planning trends were discussed earlier in the section on "Current Implementation of the Act." In the Copenhagen region, we plan to add a series of modern residential facilities which embody our latest thinking in this field. Our experience has shown that approximately two per thousand of the total population are in need of a residential place in a service system. Thus, the following additional facilities are being planned for Region I.

1. A residential center in Copenhagen, approximately 2.5 miles from the middle of town, for about 300 moderately to mildly retarded adult men and women. Half of these residents will require no special assistance and can live in their own rooms, each with a small entrance hall, washbasin, and built-in cupboard. The other half will have physical handicaps requiring other types of dwellings. Beyond dwelling units for residents and staff members, this facility will have a heating plant, an administration building, a kitchen building, store building, shops, workshops, wards for patients with acute illness, wards for somatic observation and examination, a building for physiotherapy, living units for educational activities, assembly hall, canteen, and a church.

2. Other types of modern buildings are planned to relieve Lillemosegard, which has to struggle with overcrowded living units and long waiting lists, as do many of the Danish institutions for

for the retarded. Thus, we are planning a hostel at Valdermarsalle (near Lillemosegard), with dwellings for approximately 50 mentally retarded men and women who work in external workshops. Each home consists of 10 single rooms in each of the two-story buildings; living rooms, dining rooms, and hobby rooms are placed in separate adjacent one-story buildings.

Finally, we should mention the recently erected John F. Kennedy Institute for approximately 15 children below age 7 who suffer from phenylketonuria, or the "Folling-disease." Besides being a home for these children, the Institute is a research center for the scientific study of phenylketonuria.

In Denmark, the tradition has been to consider the care of the retarded and the support of their families more important than research. However, the wish for better understanding of the different conditions, their etiology and development, has become more and more urgent. The equipment and resources of the Children's Hospital offer the opportunity of intensive research, and the Danish Society for the Scientific Study of Oligophrenia and other scientific societies have greatly contributed during the years to research.

Appendix 1

THE ACT NO. 192 OF JUNE 5,1959. The Act concerning the Care of the Mentally Retarded and other exceptionally Retarded Persons.

Chapter I.

Section 1.

The Danish National Service for the Mentally Retarded and other exceptionally retarded persons is carried out by a semi-independent organization under the leadership of the Minister of Social Affairs.

Subsection 2.

As laid down in Section 67 of the Act of Public Welfare, the organization is to be approved and to be under the board of directors, acting in concert with the regional centres mentioned in Section 3. The board of directors consists of 8 members, appointed by the Minister of Social Affairs, and a chairman, the Director of the Service, who is appointed by the King. One of the members, who must be an expert in the field of psychiatry, and who must not be employed by the Service, is appointed on the recommendation of the National Health Service. One member, who must be pedagogically trained is appointed after negotiations with the Minister of Education.

One member is appointed on recommendation by a country-wide Association of Parents and other relatives of mentally retarded persons, this association being authorized by the Minister of Social Affairs. The remaining 5 members are to be appointed among persons, who must be expected to have insight in and interest for the Service, so that the choice is made in a way which to the greatest possible amount secures an even representation from various parts of the country. The members who are appointed for 4 years--a period that corresponds to the electoral period for local councils--receive a salary which is to be fixed by the Minister of Social Affairs.

Subsection 3.

Pursuant to negotiations with the Minister of Housing, the Minister of Social Affairs may appoint an expert to assist the board of directors in the administration of matters concerning house-building and landscape-planning.

Section 2.

In accordance with the rules laid down by the Minister of Social Affairs it is the duty of the board of directors to administer this law, to watch the development within this field, and to advance to the Minister of Social Affairs proposals as to measures which the development may require.

Section 3.

The Minister of Social Affairs takes care of the establishment of the local regional centres for treatment, and the existence of institutions and other means which are needed to attain the target for the programme.

Subsection 2.

A board of control is to be appointed for each regional centre to control the functions of the service, and jointly with the local regional management to administer the institutions placed within the area in question in order to attain the target for the programme. The members of the board of control may get a fee, to be provided for on the yearly estimates.

Subsection 3.

As a rule, the regional managers of the Service should be summoned to the meetings of the board of control.

Subsection 4.

More detailed rules as to the establishment of regional centres and the setting-up of boards of control will be laid down by the Minister of Social Affairs.

Section 4.

The Minister of Social Affairs shall set up a tribunal (the Central Tribunal) consisting of a chairman who must fulfill such conditions as prescribed for a High Court Judge, a social trainee, and an expert in psychiatry, who is independent of the Service, and decisions as to the initiation and termination of relief measures are to be brought before the tribunal after decisions, made by the chief physician in question, in accordance with Section 9, subsection 5, point 2, and Section 10.

Subsection 2.

The tribunal itself lays down its rules of procedure.

Subsection 3.

The costs of the tribunal activities (incl. salaries to constituting members and secretary) are to be paid by the State and should be provided for in the yearly budget.

Chapter II.

Initiation and Termination of Relief Measures

Section 5.

Entitled to receive help and assistance from the Service are those who are mentally retarded or whose state may be considered as ranking with mental retardation, and who may be estimated to be in need of provisions for care.

Section 6.

Request for help and assistance or termination of same can be advanced by the person in question or by other persons or authorities on whom, according to the circumstances, the responsibility rests to attend the affairs of the person in question, of, also Section 7.

Should the authorities within the Service otherwise learn about any person who may be considered in need of relief measures from the Service, the authorities in question shall bring about the necessary investigations in order to verify, whether assistance in any form should be given. If this should be deemed to be the case, the Service must give necessary instructions accordingly, and must, where necessary, arrange for the initiation of relief measures.

Subsection 3.

When the conditions for upholding the relief measures are no longer deemed to be present, these should be brought to an end, and it rests with the chief physician in question to see that this be carried out.

Section 7.

The Minister of Social Affairs shall lay down rules concerning the extent to which public authorities, physicians, teachers and other employees who through their working activities are in touch with the mentally retarded and other subnormal persons, are to furnish reports to the Service. The rules concerning furnishing of reports from physicians and teachers shall be laid down after negotiations with the Minister for Home Affairs and the Minister of Education.

Chapter III.

Particular Provisions concerning Children and Adolescents.

Section 8.

The necessary instructions regarding nursing, treatment, etc. as well as the provisions which may be available to the Service for help and assistance should be extended to those parents with children who are mentally retarded or whose state places them on the same level as mentally retarded children.

Subsection 2.

In so far as the instructions of the Service are not complied with, the assistance of the Service can be granted only in accordance with the rules in Section 11 of the Act of Public Welfare.

Section 9.

A child, who is mentally retarded, or who through his state is on a level with mentally retarded, and who for this reason cannot follow neither the ordinary primary school education nor the special educational systems for less gifted children, established within the frames of the ordinary school, of. Section 2, subsection 2, and Section 29, subsection 2 in the Law-regulation No. 220 of June 18, 1958 regarding primary schools is subject to compulsory education and training according to the specified rules, stated in this Act.

Subsection 2.

The compulsory education and training comes into force, when the child in accordance with the current rules as laid down in the Act of Primary School Education would normally be subject to compulsory education, and continues ordinarily until his reaching the age of twenty-one. In particular cases the obligation can be ended at an earlier date, however not before such time as the normal termination of compulsory education according to the Act of Primary Schools. More specified rules on this subject are to be laid down by the Minister of Social Affairs.

Subsection 3.

The compulsory education and training is regarded as fulfilled when the instructions of the Service have been complied with.

Subsection 4.

The compulsory education and training may be fulfilled as home-tuition or in any other way in which provisions are made for the education, training and general development of the person in question, in so far as this does not conflict with the interests of the person in question.

Subsection 5.

When the compulsory education and training is not fulfilled, assistance from the Service can only be granted in accordance with the rules in Section II in the Act of Public Welfare. As regards adolescents aged 18 till 21, who are not covered by the rules in Section II in the Act of Public Welfare, the Service itself makes its decisions with regard to the fulfillment of compulsory education and training. The person in question or one who acts on his behalf, may request that the decision reached be submitted to the Central Tribunal for settlement. Besides, the rules in Section 10, subsections 5 and 6, and Section II are correspondingly applied.

Subsection 6.

With the approval of the Minister of Social Affairs, and after negotiations with the board of directors of the Service, financial aid may be granted to the establishment and upkeep of municipal and private institutions for mentally retarded persons.

Chapter IV.

Special Rules concerning Adults.

Section 10.

Any person over 18, who is mentally retarded or whose state may be placed on a level with the mentally retarded persons, and who is not covered by the rules in Chapter III, is obliged to receive help pursuant to this Act, in so far as the chief physician in question should deem the said person to be regarded as dangerous for himself or other people.

Subsection 2.

According to Section 1, the initiation of relief measures can only be effected on the basis of a statement from a medical practitioner, who is not employed by the Service.

Subsection 3.

When an application for termination of relief measures is submitted, the chief physician in question should as soon as possible and within a fortnight come to a decision, whether the application should be complied with or not. In other cases than those mentioned in Section 1, application for the termination of relief measures may not be refused, unless the termination of these measures is presumed to create essential nuisance to the person in question. Together with the information on the decision made, the person in question should be informed of his access to claim the submission of his case to the Central Tribunal, mentioned in Section 4.

Subsection 4.

The decision made regarding the initiation or termination of relief measures can by the person in question or by one who acts on his behalf, be requested submitted to the Central Tribunal for settlement.

Subsection 5.

The Central Tribunal shall settle the question as soon as possible, and within one month after receipt of the appeal. The settlement should be come to by ordinary majority, and the grounds for the judgment should be given.

Subsection 6.

If the Central Tribunal has settled a case, no other appeal to the Tribunal can be made until a year after the date of the first settlement, unless the Tribunal has fixed an earlier date. In case of legal decision, the time-limit should be calculated from the date of passing of the sentence.

Section 11.

The settlements of the Central Tribunal can, within one month, be appealed to the Court for settlement in accordance with the rules laid down in Chapter 43.a. in the Administration of Justice Act. The request of submission to the court may be forwarded by the person in question or by a person who acts on his behalf.

Subsection 2.

If the Central Tribunal has passed a decision, made pursuant to Section 9, subsection 5, point 2, or Section 10, the person who has appealed the case must together with this fact be informed on his access to request the case submitted to the court, and the date fixed for this submission must be given.

Subsection 3.

When the legality of the Tribunal's settlement is affirmed by judgment, the request for re-examination cannot be made with obligation for the Service to submit the case to the court in accordance with the Administration of Justice Act, Section 469, until one year from the time of the judgment, unless the court should fix an earlier date.

Subsection 4.

The rules in this section should apply correspondingly to cases in which the chief administrative officers of the state have made decision of initiation of measures for care of those mentally retarded persons whose mental state involves danger to law and order.

Section 12.

In cases when relief measures have been initiated or terminated, pursuant to Section 9, subsection 5, point 2, or Section 10, it rests with the Service, at the same time as it makes the decision, to advise accordingly the probate court on the domicile of the person in question (in Copenhagen: The Municipal Corporation), in order to have a qualified and willing guardian appointed. Unless circumstances prevent, the wish of the person in question should be taken into consideration on the appointment of the guardian.

Subsection 2.

In other cases than those mentioned under Section 1, it rests likewise with the Service to cause a guardian to be appointed, i.e., if the mentally retarded person himself requests so, or it is otherwise so indicated by the circumstances.

Subsection 3.

The guardian has to keep himself informed of the condition of the mentally retarded persons and to see that relief measures be not upheld for a longer period than necessary.

Section 13.

At the request of the Service it rests with the police to assist at the initiation of relief measures, and at the bringing before the court of the person in question--in accordance with more specified rules, laid down by the Minister of Justice after negotiations with the Minister of Social Affairs.

Chapter V.

Divers rules.

Section 14.

Payment for relief measures offered by the Service is fixed by the Minister of Social Affairs in accordance with the rules laid down in the Act No. 77 of March 14, 1934, concerning fixing of payment for persons who are taken under special care according to the Act of Public Welfare. No payment, however, should be made for stay in kindergarten, schools, sheltered workshops, and corresponding facilities of the Service for the admission to which neither hospitalization nor placing under observation in institutions is necessary; see, however, Section 15.

Subsection 2.

Provided the person in question or his supporter should not be able to make the fixed payment, the rule, laid down in Section 69, subsection 3 of the Law regulation No. 329 of November 19, 1958, concerning the Act of Public Welfare should apply. The rule laid down in Section 12, subsection 2, point 1 of the said regulation also applies to children over 15 years who receive help from the Service.

Section 15.

The rules concerning initiation and termination of measures for the care of mentally retarded persons pursuant to sentence and concerning placing under observation at the institutions of the Service pursuant to a decree by court, are not affected by this law.

Section 16.

This Act comes into force on the 1st October, 1959.

Appendix 2

Training of Care Assistants at the Personnel High School in Copenhagen.

Care Assistants

"Care assistants" handle the daily training, treatment and occupation of mentally retarded persons admitted to residential facilities of the Danish National Service for the Mentally Retarded. They perform functions similar to attendants, aides, and cottage personnel in the United States. Candidates for such work are supposed to be interested in human beings, to take pleasure in helping those who are in need, to be patient and willing, and to be able to help mentally retarded children and adults in recreation, occupational activities, training or work.

A care assistant may either be employed at large institutions, or at smaller residential homes such as nursing homes for children or adults, school homes, or homes for the aged and sick; or he can, if he so desires, get a job with a hostel, a sheltered workshop, or similar facilities.

Education of Care Assistants

Young men and women with some education beyond primary school can be admitted to the Personnel High Schools, which provides theoretical and practical training of care assistants for all of Denmark. The trainees are somewhat similar to high school drop-outs in the United States, in that they have more than 8 and less than 12 years of education.

Basic training lasts 3 years. It consists of approximately 1,640 lessons on theory, given at the Personnel High School, and of extensive practical training given at one of our 11 regional centers.

Training commences with 3 months of practical training at one of the institutions for the mentally retarded, during which period both institution and trainee attempt to ascertain whether the trainee will be suited for the job. If so, the trainee receives 5 months of theoretical education, followed by 10 more months of practice at the institution where he started working. Thereafter, the trainee continues theoretical education at the Personnel High School for 5 months, after which he works an additional 13 months. Basic training is then terminated by a final examination.

The most important training topics are pedagogy and psychology. The aim is to acquaint the trainee with the ideas behind these disciplines in order to create a greater understanding of his retarded fellow citizens and their handicaps. Under psychology, various aspects of the etiology and management of mental retardation are discussed, such as heredity and environment, brain damage, mongolism, debility, pseudo-retardation, sterilization, examination methods, and therapy.

The trainee learns by clinical demonstrations about blood types, metabolic disorders, psychosis, autism and neurosis, epilepsy, spastic paralysis, character deviations, and medicamentary therapy. Discussions are held about the background and treatment of different forms of maladjustment, especially those resulting from puberty disorders, and about the special reasons why physical and psychological handicaps demand special treatment. Training is given in the treatment of mentally retarded children in institutions; in geriatrics, in order to make the personnel qualified for taking care of old patients; and in workshop instruction. Frequent excursions to various institutions for the handicapped are carried out.

In addition, the following topics are taught: organization and structure of the National Service; education; psychiatry; drawing, painting, modeling, etc; needlework, etc.; gymnastics, ballgames, dance; arithmetic; first aid; elementary judo; anatomy and physiology; and mental health. Lessons in singing and music are given to make the trainee interested in this field and to enable him to share his experience with others. The trainee is introduced to music-reading, vocal-culture, technique of singing, etc. Socials science and civics are taught in order to outline the structure of Danish society, and to understand relations to foreign countries for later discussions of social questions. These instructions, plus instruction in language skills, extend the trainees academic skills and education.

In connection with the physical training, care assistants learn:

1. The motor development of the healthy child so as to gain skills in evaluating the motor age of mentally retarded children and thereby be able to choose suitable games and toys.

2. Various forms of muscular work; training of muscular strength and circulation.

3. Methods and means of promoting suitable coordination.

4. The human statics; carriage (posture) analysis and correction.

5. Working techniques; especially lifting techniques.

Part VI: Model Service Models

Chapter 11

A Rural County in Sweden: Malmohus County

Karl Grunewald
Swedish National Board of Health and Welfare

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A RURAL COUNTY IN SWEDEN: MALMOHUS COUNTY

Some General Facts

At the end of 1966, the population of Sweden was 7,800,000, with roughly 4,200,000 persons living in urban areas. During that year, 125,000 births were registered.

The country is organized into 25 counties and 3 county boroughs, the latter being the metropolitan areas around Sweden's major cities: Stockholm, Gothenberg, and Malmo. The counties vary in population between 58,000 to 424,000, with an average of 250,000.

A county council, whose members are elected by the public every 4 years, is responsible for local government with respect to certain matters such as health services, children's homes, vocational training and rehabilitation. Such councils meet twice a year for sessions lasting 3 to 5 days during which budgets are approved and general policy guidelines laid down for the coming year's activities. Administrative and executive power is vested in the county council's board of administration.

The county councils have an unrestricted right to levy taxes. The rates are based on the same system used for municipal taxes, and the national average is between 5 percent and 7 percent of the taxpayer's net income.

The Organization of Health-Related Services in Sweden

Sweden has more hospital beds and days of hospitalization per capita than either the United States for England and Wales. It also has a lower mortality rate and longer average lifespan. It is unclear, however, whether or not the liberal access to medical and hospital care has reduced the extent of disease and invalidism among the Swedish population.[1] Data on health-related expenditures in Sweden, and comparisons of patterns of such services between Sweden, the United States, and England and Wales are presented in Tables 1 and 2.

Health-related services in Sweden are today organized at three geopolitic levels: the county level, averaging between 200,000 and

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[1] Peterson, O.L., Burgess, A.M., Berfenstam, R., Smedby, B., Logan R.F., & Pearson, R.J. What is value for money in medical care? Experiences in England and Wales, Sweden and the United States, Lancer, 1967, 1, 771.

Table 1

Comparison of Sweden, U.S.A., and England and Wales on Various Aspects of Medical Care

Country	Ambulatory service use	Hospital use	Expenditures	Death rates
U.S.A.	High	High	High	Highest
England & Wales	High	Low	Low	Average
Sweden	Low	High	Low	Lowest

Table 2

Growth of Combined Expenditures(including Investments) by the State, Public Health Insurance Funds, the Counties and County Boroughs Between 1959 and 1965

Types of Expenditures	Total Expenditures 1959	Total Expenditures 1965
Health and medical care, total	$436 million	$915 million
Per capita	58 million	120 million
Breakdown:		
General hospital care and maternity	41.2%	42.7%
Care of the chronically sick	5.3	5.8
Mentally ill	13.4	13.0
Mentally retarded	3.2	4.3
Epileptics	0.3	0.1
Public health nursing	1.7	1.4
Prenatal and child welfare	0.7	0.6
District midwifery	0.4	0.2

N.B.: The increase in the expenditure for the care of the mentally retarded was relatively highest. In 1966, it amounted to 4.5% of all expenditures.

300,000 people; the regional level, covering roughly one million people; and the total or national level, which involves close to eight million people.

Planning, organization, administration, and financing of somatic hospitals in Sweden has been entrusted to the local authorities throughout the 200 years during which we have had hospitals in the modern sense of the word. An increasing trend in the planning of health and medical sick care in Sweden is a growing integration of all services under a single authority--the county councils. Over the years, the counties have been given or have assumed the responsibility for the tasks involved in the national health services decreed by Parliament. Among other things, this includes responsibility for mental hospitals and the care of the mentally retarded. This responsibility has grown to such an extent that today the operation of hospitals and other health service agencies accounts for 80-85 percent of the counties' total expenditures.

In accordance with a government decision, Sweden has been divided into seven multicounty geographical areas ("hospital regions") which are to function independently regarding inpatient care. Each regional hospital is to have specialty clinics to handle diseases the low prevalence of which does not warrant specialized facilities at the county level.

In many different branches of medicine, the following line of development can be traced in the struggle to balance between centralization and decentralization. Initially, specialized institutional care was at the total or national level, owing to the shortage of local facilities. It was thus isolated from the local level in the rehabilitation process. However, this situation gradually changed with an increase in the resources available at the local and county levels as smaller facilities in different specialities were established. It thus became no longer necessary to send persons to faraway hospitals or institutions.

An interesting aspect of this line of development is that with increased technical and medical resources at the county level, the need for specialization grows as a natural result of the efforts of certain progressive specialists. Regional units are thus created as an extension of the improved and continually more advanced local facilities.

At present, the first receiving agencies identify individuals who require more specialized forms of care at higher levels. The size of the facilities being established at the regional level is determined by prevalence, demographic factors, and the number of special problems that justify the services of a specialist.

The higher the level of care, the more restrictive the form of care will be and the more activity there will be in an around a resident's bed. In other words, it will become a matter of specialist care and thus proportionally more expensive. Or looked at from the opposite angle: the lower the level, the more the bed will, as it is for the rest of us, become a place to sleep, and day activities, as in boarding homes, will take place outside the facility. The staff's work will become more collective and efficient.

The chief motives for regional care are rational and economic ones. In addition, there is wider scope for further progress within a specialty through research and training. It must be emphasized that the decisive factor for any successful care program is a functional interrelationship between the various levels.

Planning and Organization of Services to the Mentally Retarded

Planning Considerations

Ever since 1954, Swedish legislation regarding services for the mentally retarded has been comprehensive. This means that with the exception of certain general provisions such as those contained in social security legislation, a single law enumerates all these services that must be provided for retardates. Most of these services are provided on the county level, while certain special ones are on the regional level, and practically nothing on the national level.

There are three basic requirements that must be fulfilled if the planning of the various services for the mentally retarded is to proceed smoothly and with an ethically well-balanced division of responsibilities. These are (1) a law and an expert agency which ensures that law is followed, (2) an implementing agency rooted in a democratic system, and (3) representation from the consumer of services.

The law should preferably cover all the various forms of special services required by the mentally retarded. The 1954 legislation regarding the mentally retarded has been mentioned above. The responsibility for the implementation of this legislation lies with the National Board of Education and the National Board of Health and Welfare. In these two Boards, there are roughly 15 officials representing the fields of medicine, pedagogy, psychology, social welfare, and jurisprudence with regard to the mentally retarded. Their supervisory duties are not so much in the form of inspection visits to the individual facilities, but rather advisory and consultative. An important part of the work carried on by such personnel involves the arranging of courses and conferences, and of educating politically appointed members of the ccunties's boards of services for the mentally retarded.

The plans drawn by the various county councils for the implementation of the law are approved by the central authorities, as are architect's drawings for the buildings, the number of places, the qualifications of the chief officials and administrators at the facilities, etc.

A more direct influence on planning is achieved when representatives for the two central Boards confer with the county boards of services. This gives the former wide scope for initiating and controlling the planning process. At the government (national) level, these two Boards, of course, will represent the opinions of the county boards in committee work, statistical studies, etc.

One-sided pressure from above is not always alone sufficient to activate the county councils. It is just as necessary to have some kind of pressure coming from below from those who represent the "consumers." They are the only ones who can provide detailed and shaded descriptions of all the services required by the mentally retarded. The trick or finesse is to give as little help as possible as early as possible, and not, as was done previously, nothing for a long time and then everything all at once. It may be important for parent associations and similar organizations to start day activities and counseling services themselves, but only turn them over as soon as possible to the county council. In order that they may be in a position to critisize and influence the county council, it is in our opinion wrong, in principle, for parents' associations to run facilities themselves. In Sweden, the few homes in this category are for the short-term care of children.

The planning process for the services for the mentally retarded as carried out by a county council follows much the same lines as the planning of other health and medical care services. Naturally, there are occasionally differences of opinion between the board for services and the government agencies which approve actions and grant funds. In this aspect, however, the boards are greatly aided in that there is no other group in Sweden which has its social, pedagogic, and medical needs and rights written in the law so strongly and in such detail as the mentally retarded.

In planning residential services, a number of arguments bear upon the determination of the optimal size of facilities. In favor of small facilities are the following arguments:

1. Greater proximity to residents' own home towns and relatives is made possible. This is an important and often decisive factor in the rehabilitation of retarded persons. It allows more visits, better emotional ties with people and things outside the institution, and more frequent periods (hours, days, weeks or months) outside the institution. (See Fig. 1.)

2. It is easier to integrate the residences socially and geographically within the community. Larger residences require such large closed-off areas that they tend to be excluded instead of included in the community.

3. Both the retardate himself and the community regard the retarded as less odd a person, and his handicap as a less severe one, as a result of the wider social contacts made possible in 1 and 2 above.

Against the relatively small facilities are the following arguments:

1. A small number of retardates do not "warrant" certain technical facilities such as gyms, swimming pools, sheltered workshops, dental care.

2. A small number of residents do not provide an adequate base for differentiated care, specialist examinations, and the employment of staff specialists, whether on a full-time basis or as consultants.

3. The staff feel isolated and do not obtain the same opportunity for teamwork, further training, etc.

To us, in Sweden, the advantages of the small residences are so clear that it is generally accepted that everything must be done to enable the majority of the mentally retarded to be cared for in such residences. It is thus important that the mentally retarded receive residential care which involves a minimum of encroachment upon their freedom to develop, but which is still sufficiently effective. For this reason, residents must be screened so that the relatively small number who require a greater degree of specialized care and comprehensive facilities receive them, but, in such cases, at a higher level. A person or facility with the responsibility for caring for a retardate will, in a properly organized system, never lack the necessary assistance: there will always be a back-up facility, a next step to which the retardate can be referred and where care of a more specialized nature is available. Naturally, the highest level will then be without any form of back-up facilities. However, this level will have at its disposal the resources for a miximum effort; and furthermore, the number of retardates being screened to this level will be relatively few in number.

Services for the Retarded at the Regional Level

Principles. Whether they be for somatic or mental problems, the aim of regional care facilities is to provide efficiently organized services

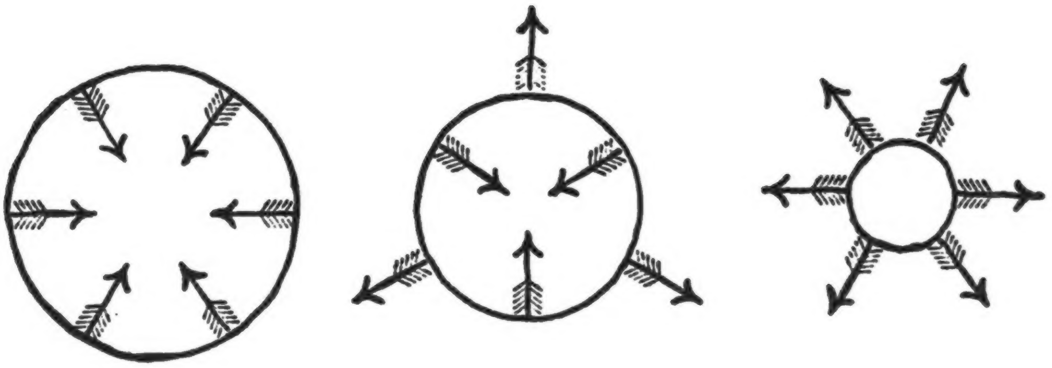

Figure 1: The Resident's Opportunities for Social Contacts in Large, Medium-Sized and Small Institutions.

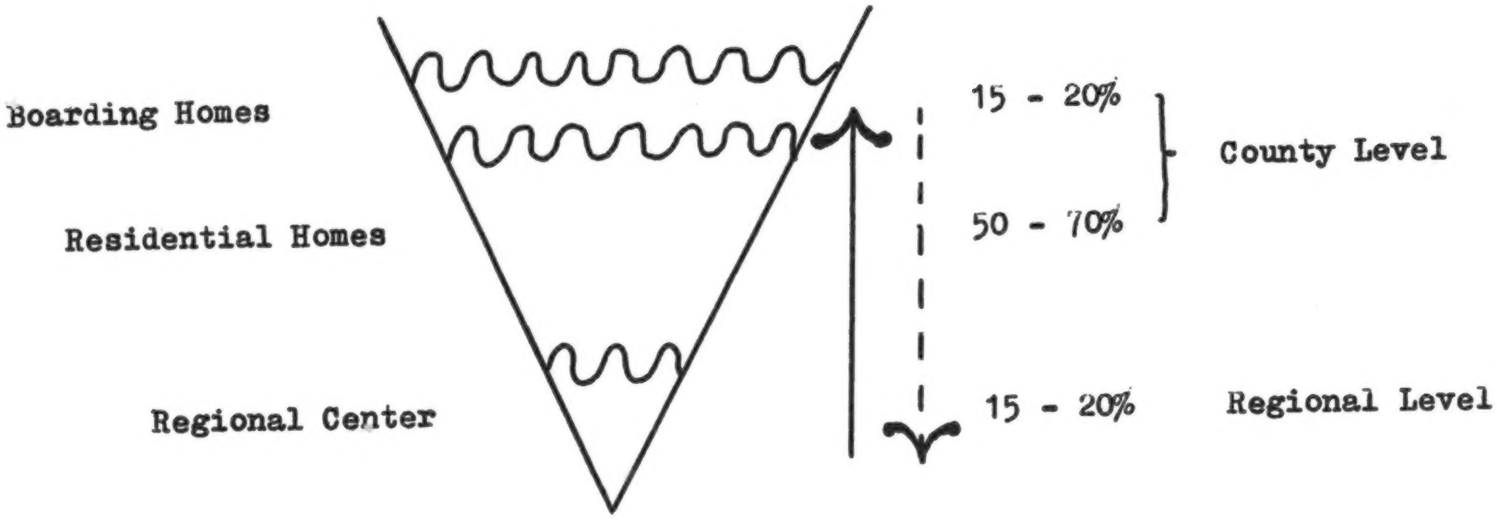
Boarding Homes
Residential Homes
Regional Center
15 - 20%
50 - 70%
15 - 20%
County Level
Regional Level

Figure 2: Breakdown of the mentally retarded adults who require residential care, indicating the direction of rehabilitation process.

using specially trained personnel and consultants. With the aid of special techniques and drugs, the mentally retarded can be brought to the state where they become receptive to activational and rehabilitation programs. Even low functioning retardates can in this way be induced to participate in meaningful activities to an extent once considered impossible. If regional care is to be progressive in diagnostic and therapeutic methods, it must be linked with a university and research center.

There are three basic requirements that must be fulfilled if a regional residential center for the mentally retarded is to function in a satisfactory way:

1. The center must fulfill a well-defined need by providing the special facilities for care, research, and training that cannot be made available at a lower level.

2. It must have good geographic and administrative ties to other specialized facilities and research activities.

3. It must be integrated administratively with the county levels. This enables the staff at a regional center to have the opportunity of keeping up with new techniques in diagnosis and therapy, and of passing this knowledge on to the lower care levels.

When planning a regional residential center for the mentally retarded, the following seven considerations are of importance:

1. The population base. The optimum seems to be roughly one million. This figure can be raised in densely populated areas and correspondingly reduced in more sparsely inhabited parts of the country.

2. Demographic factors and the available means of communications.

3. The number of persons requiring long-term and short-term care.

4. The optimum size of the regional unit, which seems to be 200-400 beds.

5. The location of the regional unit in relation to other facilities and to research and training centers.

6. Specialists require a certain number of patients and patient turnover in order to obtain sufficient practice and experience.

7. In metropolitan centers, with populations approaching a million or more, the various departments of the regional unit can be deployed and tacked on as special departments at different local-level institutions.

According to Engel[2], a number of different special branches for somatic care can be maintained at the regional level. Only four of these are mentioned here as a means of comparing the respective need for number of beds per 100,000 population: plastic surgery, 5.5 beds; thoracic surgery, 5.5; neurosurgery, 4.1; and radiotherapy-cancer clinics, 8. The following special disciplines also belong on the regional level: special audiological laboratories; phoniatric clinics; rehabilitation centers for the neurological disabled; facilities for psychotic children and juveniles; educational and care facilities for children suffering from cerebral palsy, and for other severely handicapped children who are not mentally retarded.

The following specialities will be represented at the regional but not the county level: internal medicine; orthopedic and physical therapy; neurophysiological diagnosis; genetic and chemical diagnosis; aptitude testing for vocational training; intensive social rehabilitative care; and clinical research.

Retarded individuals who might appropriately be serviced at the regional level include groups described below:

1. The severely disabled and multihandicapped who required considerable personal attention owing to their restless, impulsive, and sometimes destructive behavior. In the initial stage, special arrangements and facilities may be needed to protect such a person from himself. There may be feeding problems in the form of refusals to eat, habitual vomiting, or certain types of swallowing difficulties. Problems in self-control may mean that the resident cannot be looked after in the customary manner or take part in group activities.

2. Mentally retarded persons with severe physical handicaps who require a period of special diagnosis and intensive treatment must also be cared for in special residential facilities. At a regional unit, the particular technical resources for their care can be made available, and any aids that might be required can be tried out.

3. Retardates suffering from epilepsy may need care in a special facility, particularly if the use of drugs does not relieve them from numerous of severe attacks in which they may injure themselves

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[2] Tottie, M., & Janson (eds.). Regional Hospital Planning. Nordiska Bokhandeln, 1967, Stockholm.

or others. They may also be strongly behaviorally affected by their epilepsy, and exhibit such peculiar behavior that their presence would have a detrimental effect on group associations in a smaller residential home.

4. Regional care will be needed for the small group of blind retardates who, after training at a special school, have mastered braille and can benefit from special technical facilities such as occupational therapy. In their case, an attempt would first be made to place them in a freer form of residential care. Regional care can often be made to have the character of a continued period of training.

5. Similarly, deaf retardates who can make themselves understood through sign language may be in need of common social contacts, as they might otherwise be completely isolated in a small institution.

6. Mental retardates with contagious tuberculosis must, of course, receive special care. Since this affects only a small group and requires special medical facilities, the best solution is to place them together at a regional hospital.

7. Mentally retarded persons with antisocial behavior. See further below.

Apart from the long-term care facilities for the groups listed above, a specialized center must also be able to provide short-term care for periods lasting a few months. This is intended as a service to various residences at the county level for those cases requiring special personnel and facilities during a case study or treatment phase. In many cases, this extends to children and youngsters, particularly when diagnosis is combined with a therapy program. In addition, there is a group, primarily made up of older children and young adults, who require careful psychological testing of their ability to absorb vocational training.

Under the heading of "acute care" at a regional center come both somatic and psychiatric cases such as jaundice, heart disease, aggravated epilepsy, postoperative care, increased anxiety or aggressiveness among the normally easily managed, etc.

For the adult mentally retarded, Engel[3] proposed that the desired number of residential beds per 100,000 inhabitants should be 30 on the regional level and 120 on the local level, boarding and foster homes excluded.

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[3] Ibid.

As a comparison, I can mention that a new hospital plan for England and Wales dating from January 1962 calls for 130 hospital beds for the mentally retarded per 100,000 people by 1975. However, the plan did not include any differentiation regarding types or levels of residences.

It must, however, be emphasized in this context that estimates regarding the mentally retarded must be considered in relation to the size of various age groups and to demographic conditions. Regarding the breakdown by causes, it will be noted that there is a fairly high degree of concurrence in the frequency statistics for different countries with respect to the more severely afflicted mental retardates than is generally found among the less severely afflicted. And it is generally the former group that require care in regional centers.

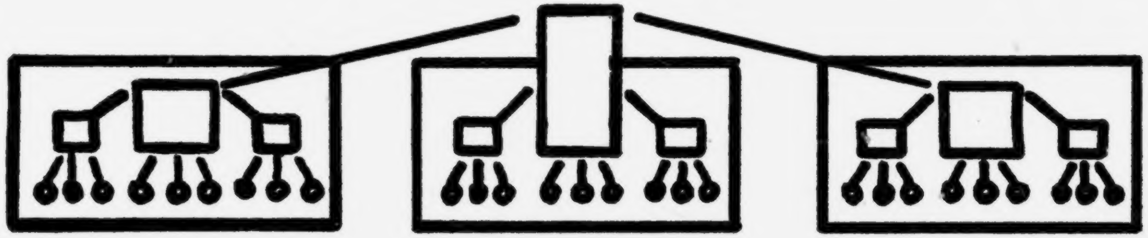
Residents in regional centers can, in principle, always be re returned to a local residential home. This also means that they will return to the proximity of their home communities. The flow of residents is thus reversible.

Figure 3 provides a schematic representation of organization of the ordinary hospital services on regional and county levels; the services for the mentally retarded are organized along the same lines.

The extent of the regional facilities is decided jointly by the member counties, but the facilities are owned and run by the county in which they are located. However, the entire responsibility for the clients still rests with the individual counties, both legally and financially.

Services for the Retarded With Antisocial Behavior. The number of retardates characterized as being antisocial is largely dependent upon how actively society helps the retardate at a preventive stage to either control his behavior or not let it lead to criminal acts. In all countries, the residential care of this group constitutes a very special problem, largely because the group includes a small number of persons who require other forms of care and confinement than the majority of retardates, e.g., those committing criminal and delinquent acts, sexual offenses, arson, etc.

In Sweden, there are as yet only four special facilities, ranging in size from 175 to 280 beds, intended for mental retardates whose behavior may be socially uncontrolled. One of these centers is for females. During recent years, the demand for such beds has dropped, and about 300 of the 900 being cared for in these institutions are actually no longer there for criminal reasons, but rather because of other mental complications, the most frequent being aggressiveness, which makes it difficult to care for them in ordinary



▯ Regional Center serving several counties with about 1,000,000 people, as well as serving as the Central Hospital for its own county.

□ Central Hospital serving a county with about 250,000-300,000 people.

▫ District Hospital serving a catchment area of about 60,000-90,000 people.

● Health Centers and Nursing Homes for long-term care serving a catchment area of about 10,000-15,000 people.

Figure 3: A schematic representation of the regional organization for somatic care in Sweden. The services for the mentally retarded are along the same line.

residential homes. Of the other 600, some 100 are not classified as mentally retarded. Among the remaining 500, about half (of which only 15-20 are women) require special forms of care. They are referred to below as psychopathic mental retardates and constitute 3 per 100,000 population.

At our mental hospitals for those who are not mentally retarded, there are roughly 700 psychopaths of normal intelligence. They make up 10 per 100,000 of the population.

It is now being suggested that in a future reorganization, the approximately 250 mentally retarded psychopaths be cared for together with the other groups of psychopaths, and not at the regional facilities for the mentally retarded. The aim of this plan is to enable the other mental retardates with antisocial and delinquent but not psychopathic behavior, now being cared for in the four special facilities mentioned, to be moved to the regional centers, or to residential homes within the various counties.

The motive for this course of action is the following. It is vital that any differentiation within the heterogeneous group of antisocial retardates is carried out with consideration to the special type of care that is desirable or necessary. At the same time, it is important that the units thus created do not cover population areas larger than a region, since the geographic distance to resident's home community and county is always an important, and sometimes decisive, factor in the social rehabilitation program. Like all other psychopaths, mentally retarded psychopaths require care facilities with relatively strict forms of custody in which there are locked quarters, special observation, and special procedures and attitudes in the personnel carrying out the rehabilitation program.

Mental retardates with antisocial and delinquent behavior who do not show any severe symptoms of criminality or psychopathy can, after detection, often be sent straight to the regional center for the mentally retarded. There they can be cared for together with the other residents or eventually placed in county residential homes. This procedure is particularly relevant for elderly persons in this group.

Two conclusions derived from programs for antisocial retardates may be mentioned here:

1. Preventive measures in the form of close supervision, provision of residential care and employment, and organized recreational activities yield greater results with the mentally retarded than with any other group in the danger zone for antisocial behavior.

2. While mentally retarded individuals may on occasion commit serious criminal acts, perhaps violent in nature, appropriate subsequent treatment may be quite mild in comparison to what is indicated for an intellectually normal person committing the same offense.

Services for the Retarded at the County Level

The current law lays down the county councils' total obligation to retardates who, because of their limited intellectual development, are in need of special services for their education, their social adjustment, or for other reasons. This is irrespective of whether the retardate is served in a county's own facilities or at the regional center. As a general rule, each county has a single agency, the Board for the Services for the Mentally Retarded, which implements the law as it affects the services for retarded children and adults.

Admission to a home or institution ordinarily requires the consent of the retardate's parents, guardian, etc., or, if the retardate is of age, he may give consent himself. Admission may take place without consent under special conditions prescribed by law.

Each county council must submit a plan for its services for the retarded for approval by the National Board of Health and Welfare and the National Board of Education. The plan must list the residential facilities required for its fulfillment. Residential facilities and schools owned and operated by private foundations or organizations must also be approved by the authorities. Such agencies may care for only those retardates directed to them by the Board for the Services for the Mentally Retarded. All services and care for the mentally retarded that are prescribed by law are provided free of charge unless the retarded person has a considerable income of his own.

Most of the retarded are served at the county level, as will be illustrated below with the example of Malmohus County.

The Services Provided by Malmohus County

Malmohus County is located at the southern tip of Sweden, across the strait from Denmark (see map, Figs. 4 and 5). Although it is one of the most populous counties, having 424.000 inhabitants and a population density of 239 persons per square mile (92/km^2), it is nonetheless considered a rural area. Some 5,500 babies are born annually within the county, and more people move in than out. The County area also encircles the city of Malmo; however, since Malmo has its own organization for health services, medical care, etc., it is not included in the county administration or this description.

The County Council is responsible for all health services and medical care for the people living within its area, and it

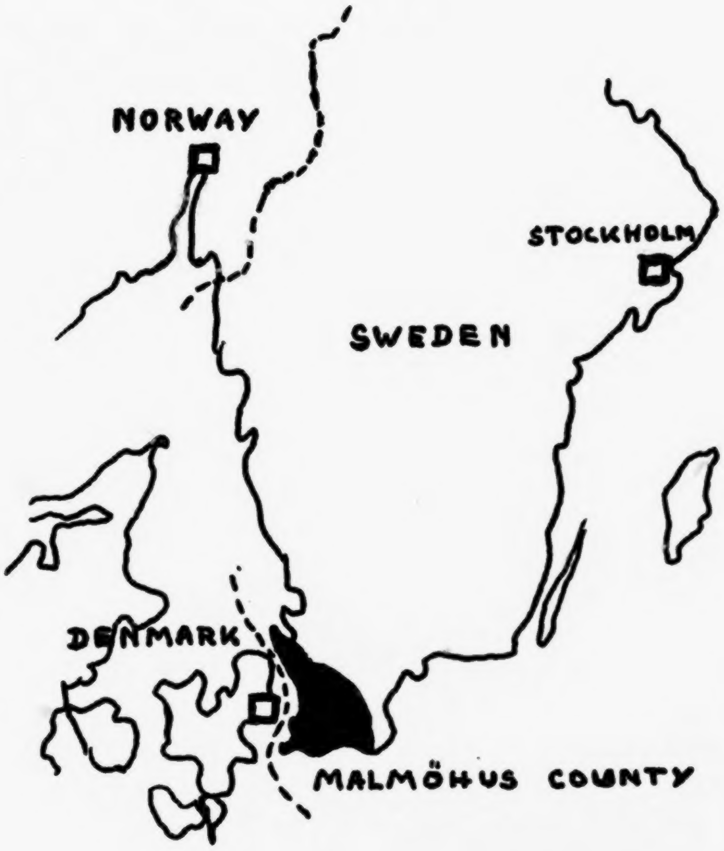

NORWAY
STOCKHOLM
SWEDEN
DENMARK
MALMÖHUS COUNTY

Figure 4: Map Showing the Position of Malmöhus County in Sweden.

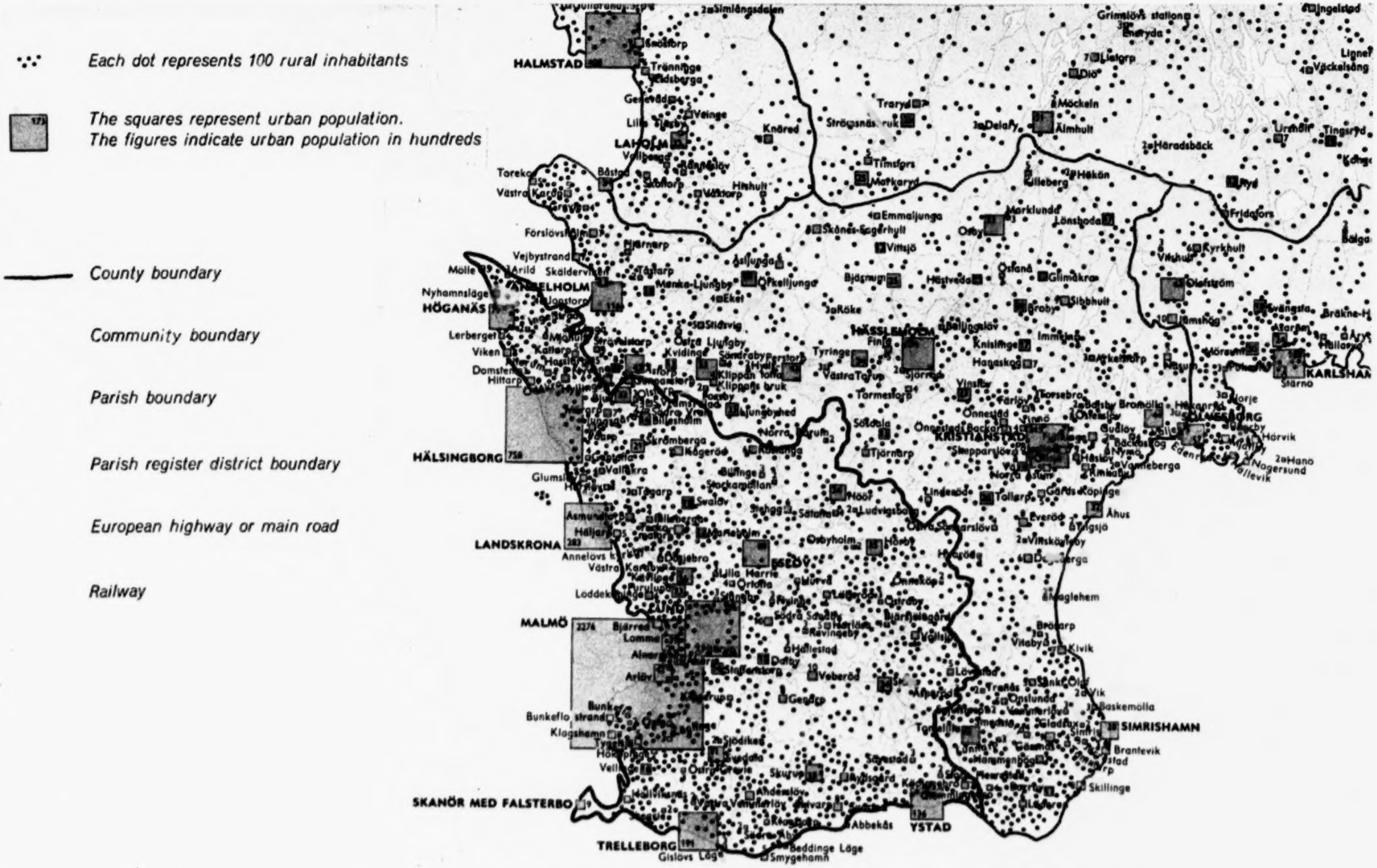

Each dot represents 100 rural inhabitants
The squares represent urban population.
The figures indicate urban population in hundreds
County boundary
Community boundary
Parish boundary
Parish register district boundary
European highway or main road
Railway
HALMSTAD
LAHOLM
HÖGANÄS
ÄNGELHOLM
HÄLSINGBORG
LANDSKRONA
LUND
MALMÖ
SKANÖR MED FALSTERBO
TRELLEBORG
YSTAD
SIMRISHAMN
ESLÖV
HÄSSLEHOLM
KRISTIANSTAD
SÖLVESBORG
KARLSHAMN
750
2274
283
194
136

Figure 5: Malmöhus County

employs 8,270 people to this end. Of these, 574 (7 percent) are employed in the training, education and care of the mentally retarded, 111 in social services, and 166 in central administration, to mention only figures of interest here. These figures include only people on the permanent staff and not temporaries, etc.

The County Council's expenditure budget for 1968 amounts to $120 million, of which $16 million is earmarked for investments and $104 million for operating expenses. Seventy-seven percent of the total will be spent on general health and medical care. While 5.8 percent will be used for the education and care of the mentally retarded, compared to 2.2 percent in 1959. While County Council expenditures are now five times higher than they were in 1959, the outlay for the education and care of the mentally retarded has risen 7.5 times.

The County Council obtains 54 percent of its funds through direct taxes, currently being levied at a rate of 7.5 cents per $1.00 taxable income. State contributions and patients' fees account for roughly 45 percent, and 2 percent is derived from loans and foundations.

The County Council operates the following facilities within the pediatric and psychiatric specialists: 3 pediatric clinics with 26, 28, and 139 beds; 2 psychiatric clinics for children with 32 and 52 beds; 1 psychiatric clinic for adults with 93 beds[4]; 2 mental hospitals for adults with a combined capacity of 2,700 beds, about 1,500 of which are occupied by patients from other counties; and 7 mental homes with a total of 506 beds.

The medical diagnosis of the mentally retarded as well as the major part of case finding is chiefly in the hands of the pediatric and psychiatric clinics. There is thus no special diagnostic agency among the services for the mentally retarded. The motive for this is a conscious effort towards "normalization": the mentally retarded (or those suspected of being retarded) should enjoy the same resources and facilities as other members of society, up until the time at which they require special facilities. It is only then that they are directed to the County Council's organization for the mentally retarded.

It is natural that not all mentally retarded individuals are registered with the Boards of Services. The under-seven age group is probably fairly large, since all are not yet diagnosed as mentally retarded. To these must be added the mentally retarded children who receive a certain degree of therapy and guidance at pediatric and child psychiatric clinics, etc. A more active detection program is being planned: a pilot project is being carried on by the county in which all four-year-olds are given a complete physical and mental examination.

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[4] Some of these beds are occupied by patients from other counties.

The County of Malmohus contains the regional center for four counties and Malmo City. This regional center is situated in Lund (population 50,000). In 1935, it was opened as Sweden's first special hospital for mental retardates on a national basis. Now serving as a regional center, it has some 700 beds for adults and 50 for children under 16. It will be rebuilt, with the exception of a children's unit which is only about seven years old. The new existing facilities will successively be torn down and replaced by now single story buildings. Eleven residents, divided into two groups, will be cared for in each living unit, grouped in complexes of three houses joined together.

Prior to its current reorganization as a regional center, a study was made of the requirements for the four counties and Malmo City--in all some 1.4 million people. The results are summarized in Table 3. The number of cases requiring long-term care at the regional center, in relation to the number of mentally retarded receiving care in the counties and the city of Malmo surveyed, was estimated at bewteen 13 percent and 21 percent, with a mean value of 16 percent.

The Mental Retardation Services Provided by Malmohus County

The Malmohus County Council has 98 members who are assembled for two sessions per year, lasting from 3 to 5 days each time. Under the Board of Administration, there are six subcommittees. One of these is called Committee for Educational and Social Services, which, in turn, has under it the Board for the Services for the Mentally Retarded.

The Board is made up of seven appointed directors and generally meets once a month. Its daily activities are handled by a central office with a staff of seven, including a "chief of care" and an assistant (both trained social workers), a psychiatric social worker, and an occupational therapist (both primarily occupied with retardates living in their own homes.) Attached to the central office staff are a school principal and a consultant child psychiatrist.

Figure 6 shows the age breakdown of the mentally retarded receiving services from the County Board in relation to 0.7 percent[5]

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[5] 0.7 percent of the population is estimated to be mentally retarded and in need of total or partial assistance. There is some controversy as to why this figure is smaller than comparable estimates in the United States. Better health services to mothers and young children, and lower rates of poverty and deprivation may partially account for the difference.

Table 3

A Survey of Specialized Regional Residential Needs for the Retarded of Region in Which Malmöhus County is Located

Types of Care	Age Groups			
	0-17 yrs.	18-23 yrs.	Over 23	Totals
Total Pop. in Age Group	355,000	133,000	889,000	1,375,000
Long-term Care				
Totals	73	76	317	466
Totals per 100,000 pop.	20	60	40	30*
Severely disabled difficult to manage on county level	36	44	199	279
Anti-social and delinquent	3	13	48	64
Severely physically handicapped	19	3	21	43
Epileptics	9	14	34	57
Blind	6	2	3	11
Deaf			3	3
Tuberculosis			9	9
Short-term Care	38	5	31	74
Acute Care	4	2	11	17

*Of these, 20 per 100,000 are in the severely disabled group.

of the age groups indicated. Figure 6 also comprises those who receive no more than state allowances, without being registered with the Board. There are 593 retardates over 16 in this category, of whom 11 percent live in mental hospitals or homes, and 8 percent in ordinary homes for the aged; 43 percent are being cared for by their parents or relatives; and 16 percent live in homes of their own.

In addition, Table 4 shows the number of mentally retarded children and adults receiving various forms of services the facilities shown in Table 5. A total of 2,100 mental retardates within the county receive some form of assistance from the community. They make up 0.5 percent of the population. About half of them receive residential care.

Mental retardation services in Malmohus County can be divided into residential and nonresidential services. However, some facilities render both types of service. I will now describe a few of the local service facilities in more detail.

Details About Nyhem

This residential facility was opened in 1902 as a private establishment near the city of Halsingborg. In 1916, the home was taken over by two county councils and cared for 109 retardates. In 1923, a separate building was erected for the moderately retarded. This building was remodeled in 1965 for 26 profoundly retarded children. In 1925 another building was added for 66 profoundly and severely retarded males. At that time, this building was regarded as a model institution because of its spacious dayrooms, special isolation rooms, large wash and changing-rooms along the corridors, a special ventilation system, and many other features. In 1963, it was rebuilt to provide care facilities for 56 residents and, among other things, the entire attic was remodeled as a sheltered workshop.

Between 1959 and 1968, Nyhem has undergone a transformation typical of Swedish institutions. A substantial decrease in the number of residents accompanied by an increase in the staff strength has resulted in considerably higher operating costs (see Table 6). However, an entirely positive result is that anxiety and aggressiveness have practically disapppeared and the residents have become more active, happier and self-confident.

Apart from attendants and domestic staff, the staff at Nyhem includes the following: 4 administrators and assistant administrators; 1 physical therapist; 2 qualified nurses; 2 kindergarten teachers; 1 handicrafts teacher; 7 occupational therapists and assistants; and 1 recreational supervisor. The attendants number 54, of which 56 percent have received the desired special training.

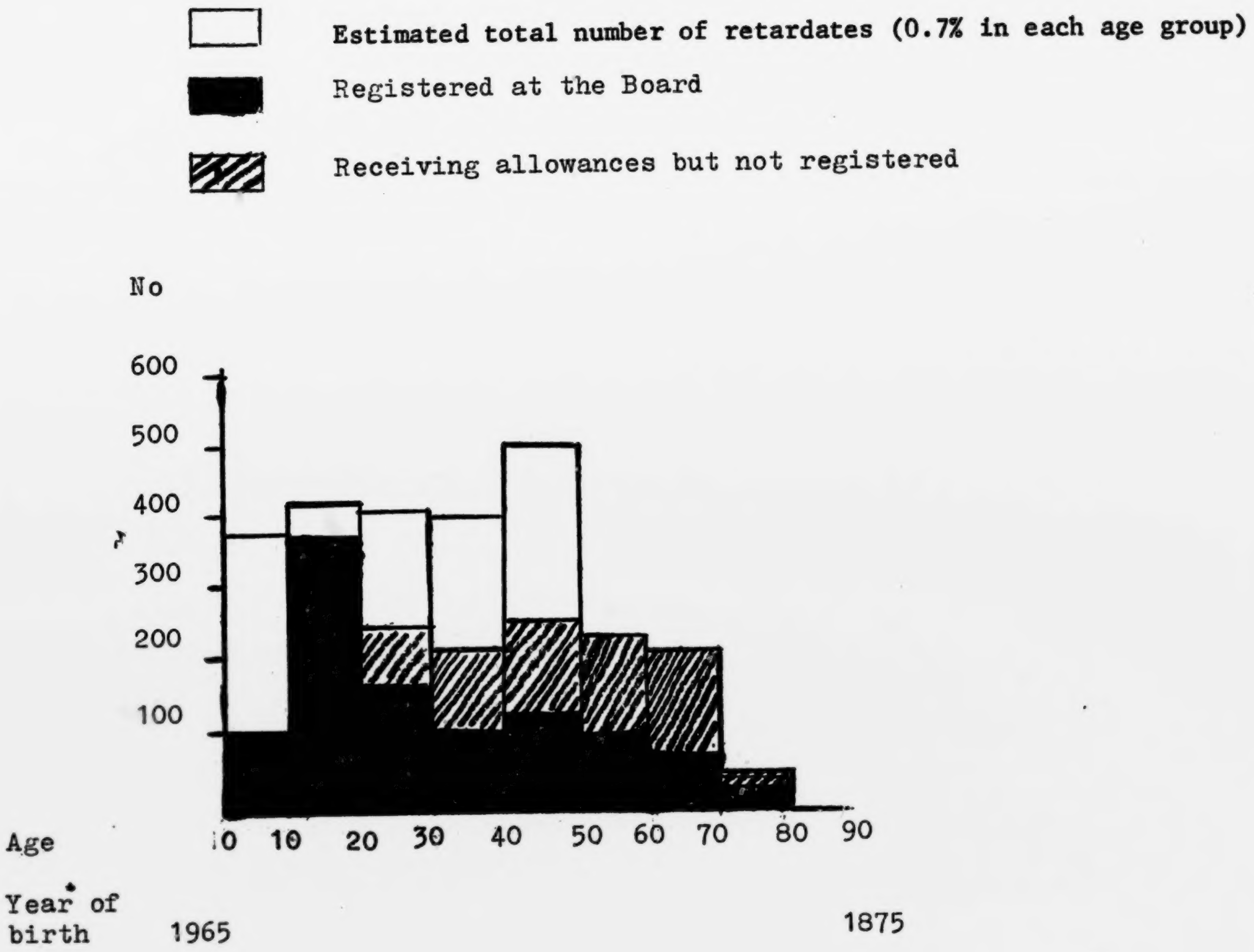

Figure 6: The Retarded of Malmöhus county by age categories.

Table 4

The Retarded in Malmöhus County and the Services They Receive

Categories	Children	Adults	Total
Boarders	278	810	1,088
Day pupils	150	41	191
Family care	1	55	56
Discharged probationally, etc.	50*	198**	248
Total	443	1,063	1,506
Percent of age group	0.55%	0.31%	0.36%
Receive allowances but not registered	—	593	—
Total		1,656	2,099
Percent of age group		0.48%	0.50%
Est. number of retardates in county			3,000 (0.7% of pop.)

*36 are day pupils

**41 attend day activities

N. B.: Children comprise the 0-16 age group

Table 5

Provisions Under the Board For the Services to the Mentally Retarded in Malmöhus County

Facilities	Residential Services		Non-Residential Services	
	Children	Adults	Children	Adults
Nyhem	26	115		20*
Möllevang School	139	36	37	3*
Georgshill		176		
Ronneholms slott		75		
Blinkarpshemmet		58		
Kullenbohemmet		25		
Osterhemmet		24		
Rabylundshemmet		23		
Furulundshemmet		22		
Klagerupshemmet		10		
Special class at Halsingborg			51	
Special class at Ystad			18	
Special class at Landskrona			8	
Vastervangen	71	48		
Day and activity home at Halsingborg			12*	2*
Day and activity-home at Lund			14*	5*
Day and activity home at Trelleborg			10*	11*
In regional centers	22	152		
At private facilities	20	46		
Foster or boarding homes			1	55
Discharged on probation, etc.			50	198
Totals	278	810	165	253
On waiting list for residential education:			11	
On waiting list for residential care:				22

*Included in the figures for those discharged on probation.

Table 6

Patterns of Change Between 1959 and 1968 in Resident, Staff and Cost Characteristics at Nyhem Residential Center

Categories	1959	1968
Residents	215	141
Staff	62	97
Residents/staff	3.46	1.45
Operating budget	$255,000	$864,000
Annual cost/resident	1,200	6,000
Daily cost/ resident	3.20	16.50

Since the center now more or less covers an entire block in a fairly central part of the city, the community has become the natural place for social training. There has thus been no need to create artificial situations within the facility. On the other hand, it is only in recent years that mental retardates living in their own homes in the city have come to the center for their daily activities, such as workshops. It is as if Nyhem has finally started to breathe.

Details About Georgeshill

Georgeshill is situated on the outskirts of Horby, a small community with roughly 4,000 inhabitants. The facility is designed for the care of 176 moderately and severely retarded adult men and women. The home was built in 1966 at a cost of approximately $2.25 million (about $13,000 per bed) and replaced an older institution which had been started in the 1920's and taken over by the County Council in 1958.

The new home is made up of six H-shaped pavilions, five being identical in layout, with 30 residents in each, and the sixth having a more hospitallike setup with 26 beds. Each residential pavilion is divided into two halves by the staff office, the toilet and bathroom units, and the kitchen. Each half is then further divided by the resident entrances into sections for seven or eight persons each. The four sections share a combined corridor-dayroom, and there is one dayroom and dining room for every two sections. There are bedrooms for one, two, or four residents, and each resident keeps his clothes in closets along the corridor. A separate building houses the administration offices, an assembly hall, and a sheltered workshop.

The 1968 operating budget at Georgeshill is $1,100,000; per resident, this amounts to $6,150 per annum and $17,000 per diem. The staff, exclusive of consultants, consists of 95 persons, with a resident: staff ratio of 1.85.

Details About Vastervangen

Vastervangen is a newly built facility for the residential care of 71 severely and profoundly retarded children and young adults. It was constructed at a cost of $1.8 million ($16,000 per bed), and has a 1968 operating budget of $690,000. Cost per resident is $5,800 per annum, or $15.75 per diem. Vastervangen is situated in the small town of Eslov (population 15,000), and lies in a residential district consisting of one-family homes, and is bounded by streets on three sides. It is thus very much a part of the community. Its location in Eslov, however, is a departure from what is considered advisable by the authorities, as it should really be in a city where pediatric and child psychiatry clinics are available. Nonetheless, Eslov has been accepted partly because of its closeness to the University

Hospital at Lund (11 miles away), and partly because Lund is overpopulated with institutions, a circumstance which has resulted in difficulties in recruiting personnel.

Various units within the facility are designed to serve different age groups. Each department has 11 or 12 beds. One building is used for personnel training, and its services are available to all the facilities for the mentally retarded within the county. Like all residential facilities, Vastervangen is also utilized for day activities for children and adults living in the vicinity.

The staff, exclusive of consultants, consists of 75, with a resident: staff ratio of 1.58. Apart from attendants and domestic personnel, the staff includes 3 administrators and assistants, 1 physiotherapist, 1.5 trained nurses, 2 kindergarten teachers, 3 occupational therapists and assistants, 4 occupational supervisors, and 1 recreational supervisor.

Details About Mollevang School

As early as 1874, a committee was appointed by the County Council to draw up a proposal for the "care and educational establishments for idiot children." In 1878, Mollevang School was opened outside Lund and has ever since served as the county's boarding school for mentally retarded children. The school has, of course, been rebuilt and expanded several times, most recently in 1957, and a special home for 35 small children was added in 1956.

In the traditional manner, there had been special units for residents who after completing their training at the school, and after becoming adults, could not return to society. It was not until this year that the last group of such adults could be transferred to other facilities, finally making Mollevang School a home strictly for children. Mollevang School is almost the last residential school in the county to accomplish this. At present, the age of the children range from 5 to about 20, but 74 percent are between 9 and 16. Most of the children have IQs between 50 and 70.

The school serves 139 boarders and 37 children who live in their own homes but come to the school every day. Five of the bedrooms accommodate 506 pupils, while all the others have three beds.

The teaching staff at Mollevang School is made up of the following: 11 general school teachers; 3 handicraft instructors; 2 kindergarten teachers; 1 housekeeping teacher; 1 physical training instructor; and 1 gardener-instructor

During the past 10 years or so, great efforts have been devoted to eliminate the boarding school character of Mollevang School so that the children get as much contact with the community as possible. One way to accomplish this was to increase the children's contact with their families. At present, about 50 percent go home over the weekend, 19 percent go at least twice a month, and 8 percent once a month. Nineteen percent go home only for major vacations, and a mere 4 percent never go home. Also, the number of children attending the school on a day basis has increased greatly since 1959 (see Table 7). As can be seen, while the number of day pupils attending special schools has increased greatly, the number of boarders has dropped slightly.

Miscellaneous Service Provisions

There are now plans to expand day-school education, and for this purpose the county had been divided into six school districts. The populations in these districts range from 42,000 to 121,000. The number of places at special schools is based on a ratio of 70 per 100,000 population,[6] corresponding roughly to 0.5 percent of children born in any one recent year. In Malmohus County, this amounts to 30 to 87 places per district. Some of these children will still have to be boarders for social reasons because of poor travel communications with the school.

The expansion of day-school services will be accomplished by establishing special classes at ordinary schools--a form of class integration. Finally, a regional vocational school will shortly be opened in another county, and Malmchus County has contracted 11 places there.

There are at present 25 men, but no women, with antisocial behavior in the special facilities for the mentally retarded in Malmchus County. It is expected that in the future, about half of these will probably be confined at the national level together with other categories of psychopaths, who are not mentally retarded, while the remainder will be cared for at the regional center and at residential homes in the county.

Fifty-five adults (and one child) are placed in foster boarding homes. These individuals are mildly or moderately retarded persons for whom the Board has assumed full economical and guidance responsibility and who are boarded with families other than their own. About

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[6] This ratio has been derived from available statistics and previous experience. No county ought to base calculations on a lower figure, while some are likely to use a higher one, up to 100 per 100,000.

Table 7

Changes in Resident Data at Möllevang School Between 1959 and 1967

Year	Boarding Pupils	Day Pupils	Probationary Discharges	Placements Into Special Schools Outside the County	Totals
1959	144	15	38	5	197
1967	139	104	95	20	362
Differences	-5	+83	+57	+15	+165

57 percent are employed on farms. All received a basic $17 per month as pocket money and were also paid wages based on performance.

In addition, there are also 198 retardates above the age of 16 who have been probationally discharged from care. The majority live with their parents. About half of these 198 are mildly retarded young people who have completed vocational training in special schools and require some form of guidance during their first year of employment. The other half are moderately and even severaly retarded persons. They are entitled to free medical and dental care and generally some form of financial aid ranging from $20 to $80 per month, over and above their state pension of approximately $80 received by all retardates. Nearly half of them work in sheltered workshops or have similar employment. About one-fourth are visited regularly by an occupational therapist, while the remainder are incapable of or have access to organized activities.

Finally, there are 50 children under 16 who have been registered with the Board but reside in their own homes; 36 of them participate in day activities. These are severely or profoundly retarded children whose parents receive $60 per month from the state, as do all parents who care for a severely handicapped child at home. This benefit is also given to parents whose children attend special classes but live at home, in all 114 children in the county. (See Tables 4 and 5)

Conclusion

If we compare our situation today with that of the preceding generation, it is easy to get the feeling that all that now remains are a few minor details, some subtle features regarding the actual design of services for the mentally retarded. However, if we look to the future and compare today's objectives with the available resources--ideals with reality--the discrepancy sometimes seems paralyzing. The ultimate solution will probably be found in a sort of following-up process in which a feedback of the results at every stage leads to further innovations in methods and actions. Elaboration of regional services (as propounded by Engel) would be one such innovation.

Part VI: Model Service Models

Chapter 12

An Urban-Rural Area in Britain: Essex County

David Norris
Bournemouth College of Technology

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AN URBAN-RURAL AREA IN BRITAIN: ESSEX COUNTY[1]

Essex County

Celts, Romans, Saxons, Danes, and Normans have all in their various season trodden the flat and fertile region between London and the sea. It is the County of Essex (see Fig. 1). Approximately 1,400 square miles (897,543 acres) in extent, Essex today has a population of 1,100,000 (see Tables 1 and 2), distributed over both high density areas as well as isolated cottages in remote districts which are ill-served by public transport. The average population distribution is 1.2 persons per acre.

Famous for oysters and witches, Essex has been witness to more than its share of political conflict and all the clamour of kingmaking. It was Essex who sent the first Socialist Member to Parliament--James Keir Hardie. Essex was the home of Lister, the pioneer of antiseptic surgery; and from this County, John Eliot left to become the first missionary to the North American Indians. Peaceful William Penn, who was schooled and lived in Essex, was later to give his name to Pennsylvania, and in some unremarkable grave in a small town near the coast lies the great-great-grandfather of George Washington. Fearful of an Essex congregation, David Livingstone chose the less complicated life of darkest Africa. The County of Essex witnessed the development of the radio industry and the innovation of the electric blanket, while less than 20 miles away, and many years ago, King Edward the Confessor complained that the nightingales disturbed him at his prayers.

All of this was many years ago. One of the precious things about time and history is its capacity to link a man with his experience and a community with its heritage. Although we no longer make kings, although we no longer take a man's life for running a deer until it is unworthy of its master's hunting, the need for change now is just as great as it was when man lived in holes in the ground.

It appears to be in the nature of man's behaviour to address himself to social problems only after these have attained urgency, and those of us who are involved in the field of mental retardation must

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[1] I am indebted to the Chairman and Members of the County Council for their permission to produce this essay, and to Dr. J.A.C. Franklin, the County Medical Officer of Health, for his help and encouragement. My thanks are also due to Mr. W.H. Leak, the County Statistician; Mr. Don Parker and Mr. David Flatt, of the Central Administration, for their ready assistance; Dr. T.A. Ramsay, of the North East Metropolitan Regional Hospital Board; and to Mrs. J. Playle for her help with the preparation of the script.

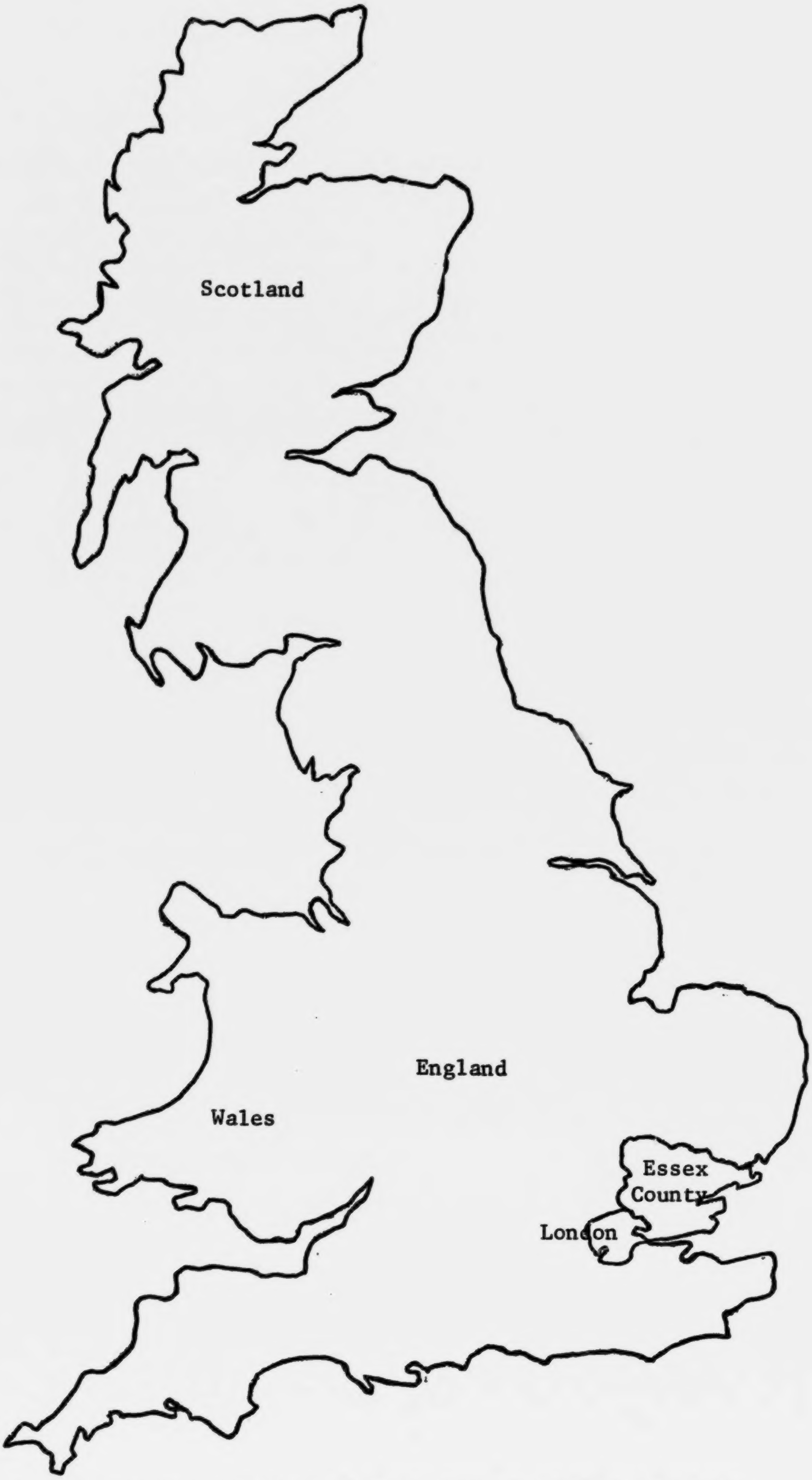
Scotland
England
Wales
Essex County
London

Figure 1.--Map showing the position of Essex County in Great Britain.

Table 1

Age and Sex Distribution of Essex Population at 1966 Census, by Frequency and Percent

Sex	Age										
	0-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65-74	75& over	Total
Males	52,350 (4.90%)	46,040 (4.31%)	40,120 (3.75%)	73,640 (6.89%)	70,100 (6.56%)	74,750 (6.99%)	63,650 (5.95%)	54,450 (5.09%)	32,630 (3.05%)	16,010 (1.50%)	523,740 (49.00%)
Females	49,520 (4.63%)	43,500 (4.07%)	36,150 (3.38%)	73,400 (6.87%)	70,860 (6.63%)	73,520 (6.88%)	65,160 (6.10%)	57,610 (5.39%)	46,010 (4.31%)	29,350 (2.75%)	545,080 (51.00%)
Total	101,870 (9.53%)	89,540 (8.38%)	76,270 (7.14%)	147,040 (13.76%)	140,960 (13.19%)	148,270 (13.87%)	128,810 (12.05%)	112,060 (10.48%)	78,640 (7.36%)	45,360 (4.24%)	1,068,820 (100.00%)

Table 2

Occupational Distribution of Economically Active and Retired Males Age 15 and Over in Essex

Occupational Classifications	Number of Economically Active and Retired Males	Percent	Approx. Social Class
Professional workers	17,170	4.9	I & II
Employers and managers	47,580	13.0	I & II
Foremen, skilled manual workers, and self-employed skilled manual workers	129,490	35.5	III
Nonmanual workers	69,980	19.2	III
Personal service workers, semiskilled manual workers, and agricultural workers	61,720	16.9	IV
Unskilled manual workers	26,500	7.3	V
Armed forces and persons with inadequately stated occupations	12,150	3.3	Excluded
Total	365,130	100.0	

greet with no surprise society's tendency to ignore the plight of the mentally handicapped while dealing with the greater problems of ignorance and poverty. It is, however, not unreasonable to suggest that one of the salient features of a well-ordered and well-developed society is both its willingness and its ability to accommodate the mentally retarded. There are many societies who are unable to meet the needs of their retarded members, but when one finds such a situation it is not always poverty which accounts for neglect.

It is not uncommon to encounter private squalor in the context of public riches, and any community finding itself in this situation must accept its own incapacity to conduct its affairs in a reasonable manner. There is, after all, no shame in demonstrating uncivilized behaviour if one is uncivilized.

In the time of the writer's grandfather, four inmates of an Essex workhouse were deprived of their Christmas dinner because they objected to being separated from their wives. And yet this same local government is now happily providing home nurses for elderly couples in order that they may stay united in their old age. This point is introduced because of the belief that if we adopt an unloving attitude now, we face our children with a harvest of administrative problems which need not have existed, but having been created require more thought, more time, and more money for their solution than need have been the case, and while these problems are being dealt with, others are being neglected.

The Mental Retardation Services of Essex County

Overview

In Essex County, as in England generally, services to the mentally retarded are provided under the mental health services, and the development of mental retardation services has been similar to that of most counties in England. At the end of the Second World War, there were no purpose-built schools or training centers[2] for the severely subnormal provided by the local authorities, and those that were available were housed in church halls or other buildings lacking adequate facilities. Throughout the whole of Britain, the growth of services for the mentally retarded represents a struggle to provide today what should have been provided yesterday.

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[2] A junior training center serves children who are mostly in the moderately to severely retarded range. In American terms, it is equivalent to a combination day care center and school for trainable children. A senior or adult training center is equivalent to a sheltered workshop and rehabilitation service, mostly for the moderately to severely retarded (eds.)

The population of the present administrative County of Essex in June 1948 was 646,000, and there were no training centers or hostels[3] for the mentally retarded provided by the local authority. By June 1967, the population had risen to just over 1,100,000, and we now provide 12 training centers and two hostels for the mentally handicapped, described in greater detail at a later stage.

Tables 3, 4, 5, and 6 show the number of retarded children and adults receiving various types of County services in early 1968. At the present time (1968) in Essex, there are 12 nonresidential training centers for adult retardates in operation, with two more being opened this year. All but two of these units are housed in buildings designed and erected in the last 10 years. The number of persons in training centers (see Table 3) is likely to be increased by about 140 with the opening of the Aveley and Thundersley centers later on this year. Of all those attending training centers at the present time in Essex, 32 percent are mongoloids.

In addition to these training centers, the County also provides one hostel for severely retarded boys and girls and one hostel for women, and the County has access to 15 beds in a hostel for men which was built by the County Council of Essex but has since passed over to the control of a neighbouring authority due to the reorganization of local government in the area and the formation of the Greater London Council. One further hostel for men is now being built and is expected to be operational this year. These units are sited as shown on the map (see Fig. 2). Table 7 details the reasons for admissions to County residential hostels in 1966.

It should be noted that a total of 465 retarded persons a year had received some kind of residential service in settings other than institutions. However, another 1,217 retardates are receiving long-term care in two regional hospitals (institutions) for the mentally subnormal (see Table 8). Thus, retardates residing under local health authority auspices still represent a relatively modest proportion of the total population receiving residential care. This question is discussed in more detail later on.

It has been the experience of the County Council that many families can quite adequately cope with a severely retarded youngster if they can be offered temporary relief in the form of short-term residential care. This service is also discussed in more detail at a later stage in this paper.

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[3] The term "hostel," widely used in Britain, is becoming increasingly popular in the United States. It generally refers to a relatively small residential unit located in the community (eds.).

Table 3

Number of Children and Adults in Day Training Centers in Essex (March 1968)

Age Groups	Males	Females	Total
Under 16 years of age	193	148	341
Over 16 years of age	183	218	401
Total	376	366	742

Table 4

Number of Mentally Handicapped Children and Adults Now Fostered Out into Private Families by Essex County Council

Age Groups	Males	Females	Total
Under 16 years of age	16	16	32
Over 16 years of age	35	37	72
Total	51	53	104

Table 5

Number of Children and Adults Offered Short Term Residential Care in 1967

Age Groups	Males	Females	Total
Under 16 years of age	101	95	196
Over 16 years of age	48	51	99
Total	149	146	295

Table 6

Number of Children and Adults Receiving Indefinite Term Residential Care in Essex County Council Hostels

Age Groups	Males	Females	Total
Under 16 years of age	13	10	23
Over 16 years of age	15	28	43
Total	28	38	66

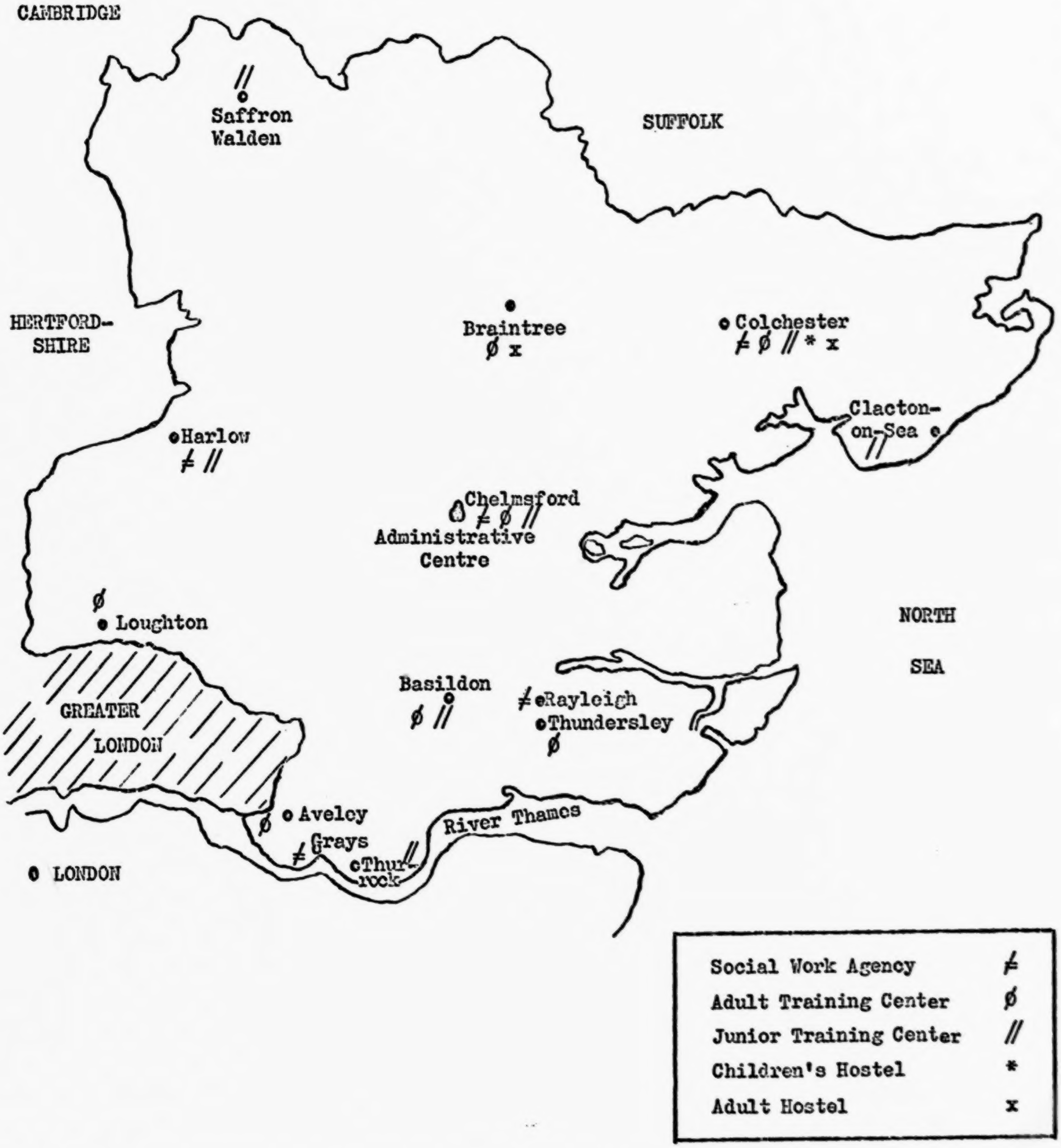
CAMBRIDGE
SUFFOLK
HERTFORD-SHIRE
NORTH SEA
GREATER LONDON
LONDON
River Thames
Saffron Walden //
Braintree ø x
Colchester ≠ ø // * x
Clacton-on-Sea //
Harlow ≠ //
Chelmsford Administrative Centre ≠ ø //
Loughton ø
Basildon ø //
Rayleigh ≠
Thundersley ø
Aveley ø
Grays ≠
Thurrock //
Social Work Agency ≠
Adult Training Center ø
Junior Training Center //
Children's Hostel *
Adult Hostel x

Figure 2.--Distribution of county facilities for the mentally retarded in Essex.

Table 7

Reason for Admission to Essex County Hostels for Subnormals in 1966

	Male			Female			
Reason for Admission	Under 16 years	16 years & over	Total	Under 16 years	16 years & over	Total	Grand Totals
Home circumstances	12	12	24	5	11	16	40
To create vacancy in an institution		1	1		15	15	16
Disturbed behaviour at home		1	1		1	1	2
Better suited to a hostel than foster care					1	1	1
Death of mother		1	1	1		1	2
Unsatisfactory housing	1		1	1		1	2
Poor health of mother				1		1	1
Break-up of marriage				1		1	1
Alcoholism in father				1		1	1
Totals	13	15	28	10	28	38	66

Note.--The term "home circumstances" embraces conditions ranging from parental rejection to families in which the presence of a retarded member produced tensions and interpersonal difficulties which ultimately led to their seeking residential care for the handicapped person. No cases of cruelty were involved in any of these admissions.

Table 8

Essex County Residents in Mental Retardation Institutions

Age Groups	Males	Females	Total
Under 16 years of age	118	79	197
Over 16 years of age	568	452	1020
Total	686	531	1217

Cost of Mental Retardation Services

Although the mental health services in the County of Essex compare favorably with any in Britain, it is interesting to note that the cost of maintaining these services is comparatively small when set in the context of overall spending by the local authority (see Table 9). Rather less than half of the public expenditures is raised locally, the remainder being supplied by funds from the National Treasury. It must be noted that the cost of providing institutions is excluded because the administration of the institutional system is conducted by Regional Hospital Boards under the control of the government.

The current cost of keeping a mentally handicapped person in one of the County Council's residential units is 18Ŀ15s.0d. ($45) a week. Separate figures for adults and children are not available, but it must be borne in mind that this figure does not include the cost of education and training. In view of the relatively high cost of residential care, it would seem to be socially desirable and economically realistic to provide housing for those families who are compelled to send handicapped children into care purely because of inadequate housing. This would have the effect of maintaining the unity of the family and reducing the economic burden on the community.

The actual cost per attendance in our training centers is 1Ŀ13s.0d. ($3.96) a day. Calculated on the average academic year, the cost per place, therefore, would be something of the order of Ŀ330 ($792) a year. The total cost of residence and education is, therefore, rather more than Ŀ1,300 ($3,120) a year.

As is apparent from Table 9, less than 1 percent of local government expenditure in Essex is devoted to the Mental Health (including mental retardation) Services. While it is not suggested that the amount spent is sufficient to operate an ideal service, it seems equally clear that the economic cost of a quality mental health service is far less than many people believe. The view is sometimes expressed by visitors to this county from Europe and North America that their own communities could not afford to operate a similar service. There is a growing belief in Essex on the part of the local authority that we could not afford to be without this service.

Table 9

Essex County Expenditures, Fiscal Year 1968/69

	Pounds Sterling	U. S. Dollars	% of Total
Education	44,050,239	105,720,574	73.43
Highways	5,129,650	12,311,160	8.55
Public health	3,213,605	7,712,652	5.36
Welfare	1,947,812	4,674,749	3.25
Fire brigade	1,480,280	3,552,672	2.47
Finance	1,272,950	3,055,080	2.12
Children's department	974,020	2,337,648	1.62
General purposes	653,120	1,567,488	1.09
County planning	452,280	1,085,472	0.75
Mental health (including mental retardation)	451,675	1,084,020	0.75
Smallholdings	175,330	420,792	0.29
Civil defense	90,000	216,000	0.15
School crossing patrols	40,290	96,696	0.07
Public protection	25,100	60,240	0.04
Records office	24,180	58,032	0.04
Local government and parliamentary	6,200	14,880	0.01
Total	59,986,731	143,968,154	99.99

Future Developments

Proposals to provide the following units in the next 8 years have been adopted:

Type of Facility	Number	Number of Places
Junior training centers	2	100 - 140
Adult training centers	6	420 - 500
Hostel for retarded children	1	24
Hostels for retarded adults	4	100
Unspecified hostels	2	50

One of the curious anomalies that has always conspired against the retarded is our failure to recognize and meet the need for advanced training over and above that normally provided by adult training centers or institutional training facilities. A very significant proportion of retarded young adults would profit by the provision of individually designed courses to prepare them for life in the open community or for semi-independent life in a residential unit. To meet this need and to provide the opportunity for long-term evaluative studies, the County of Essex intends to provide an Advanced Training Unit as one of its proposed adult centers, offering residential and nonresidential facilities to those trainees who have responded well to the routine adult center regime, or to those who leave special schools for the educationally subnormal and then show a failure to adjust adequately to independent living and working conditions.

Administration and Staffing of the Mental Retardation Service

Too often in Public Service does one find mediocre administration being produced by skilled educators or physicians and, conversely, unwise clinical decisions being reached by administrators without clinical training. For this reason it has been the custom in Essex for administrators to involve themselves in administration and those with other specialist skills to commit themselves to those areas of activity requiring the attentions of their training and experience. A flow chart of the mental health services shows the lines of communication and responsibility (see Fig. 3).

It is a matter of policy in the development of the mental health service in Essex that the management of hostels is administratively separate from the management of training centers. It was decided that

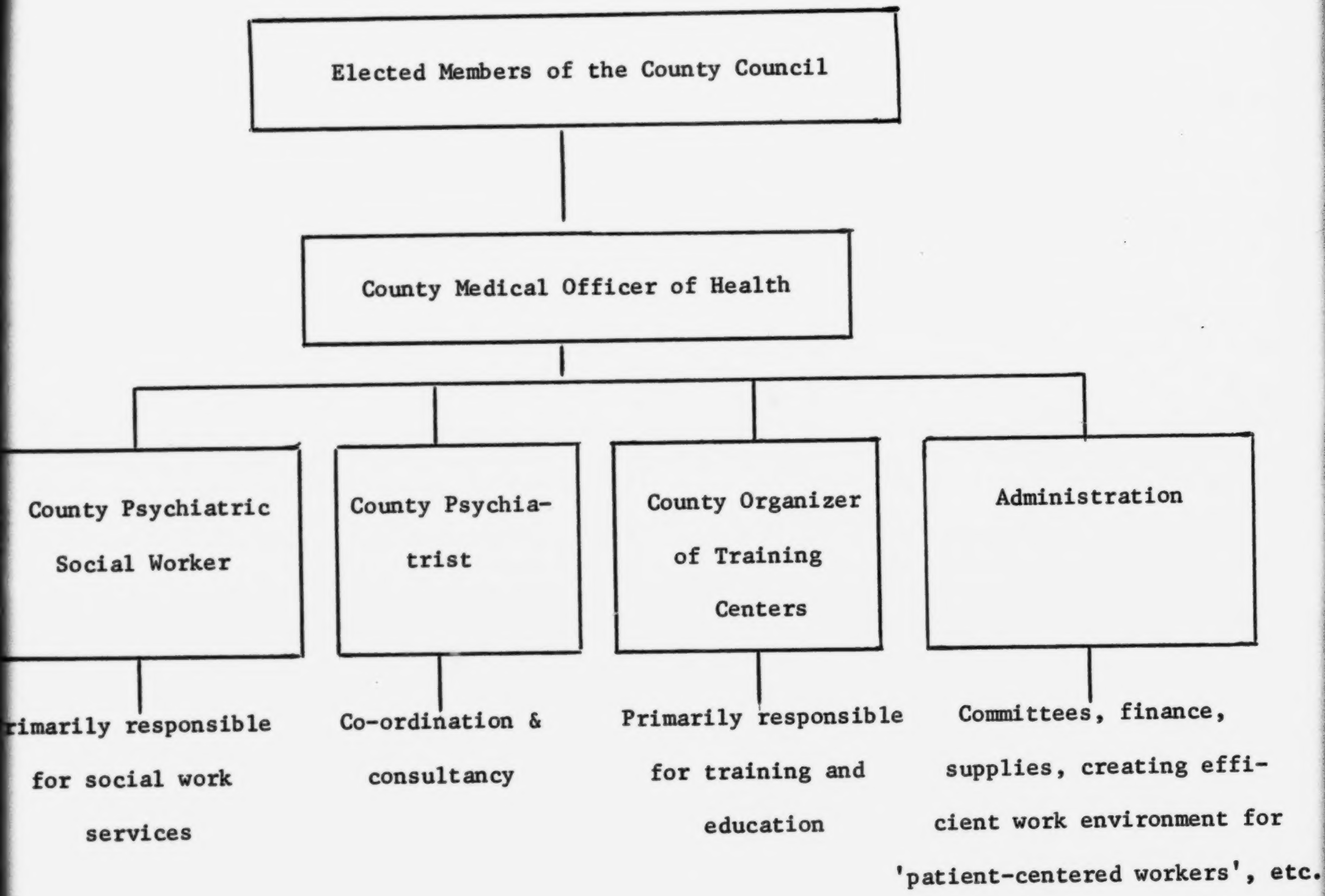
Elected Members of the County Council
County Medical Officer of Health
County Psychiatric Social Worker
County Psychiatrist
County Organizer of Training Centers
Administration
rimarily responsible for social work services
Co-ordination & consultancy
Primarily responsible for training and education
Committees, finance, supplies, creating efficient work environment for 'patient-centered workers', etc.

Figure 3. The organization of Essex County services to the mentally retarded

the person responsible for the child's education should have no responsibility for his residential care. This view was adopted because part of the underlying philosophy of education and child rearing implies a relationship between a child, his parents, and his teacher, and it was thought to be important to attempt to preserve this state of affairs for retarded children in residential care. For this reason, workers in the hostels are asked to try and fulfill those functions associated with parenthood and not to be preoccupied by the child's school life.

Children frequently use their home and family as a refuge from school, and their school as a release from home and family, and because of this sort of consideration, the teachers in Essex are not involved to any extent in the child's life in the hostel, and the staff in the hostel are not actively involved in his school life. Life can sometimes be very frustrating for children in those establishments where the adult performs the dual role of teacher and parent. Should the child get into trouble in the classroom it makes it difficult for him to go home to abreact if he is met by his teacher disguised as a houseparent.

Until little more than 5 years ago, the greater part of the burden of training teachers for the mentally handicapped was carried by a voluntary society, viz., the National Association for Mental Health. In more recent years, however, the Government has established a Central Training Council, and by September 1968, 20 courses of varying types will be available in England and Wales.

It has long been a source of some concern both to parents and workers in this field that employing authorities are still too frequently uncritical of the academic background of new entrants to the mental health services. In order to promote higher standards, the County Council of Essex has adopted the view that, while it is accepted that there are not enough specially trained workers to staff the nation's training centers, no person shall be employed on a permanent contract in training centers for children without first having passed five subjects in the General Certificate of Education and subsequently having successfully completed one of the training courses. These courses require 2 years for inexperienced workers, and 1 year for mature students having a minimum of 2 years approved experience. It is not without interest to note that in the whole county there are only two posts unfilled. This is, perhaps, even more remarkable when one considers that the maximum annual salary for trained workers in junior training centers is only £860 ($2,064).

It is a matter of extreme regret that the energetic steps taken to offer training for teachers in training centers have not been matched in the field of child care for those workers in hostels for the mentally handicapped. Many local authorities have experienced quite considerable difficulties in providing adequate staffing for their hostels. If we must have hostels, we should ensure that workers are offered a career in the field of caring for the mentally handicapped that offers both training and prospects of advancement.

The present staffing ratio of the training centers in Essex is as follows:

Junior Training Centers

1 teacher to 10 children in classes for "uncomplicated" children;
1 teacher to 4 or 5 children in classes for children with added difficulties (e.g., cerebral palsy or marked emotional disturbance);
1 general duties assistant to approximately every 20 children (these workers undertake the nonteaching tasks that surround the school life of the child).

Adult Training Centers

1 instructor to every 10 trainees.

In addition to the routine provision of teachers and instructors, there are also six posts of trainee teacher. These posts are filled by girls having the required educational attainments who are asked to work from 1 to 2 years before going on to the 2-year training course. During this initial period, opportunities are provided for them to work in training centers, day nurseries, other types of schools, hospitals, and social work agencies. When they eventually go away for training, it is hoped that they will have acquired an increased insight into the human condition and consequently make better students than they would have done without this experience.

Any staff from the training centers who are sponsored for a full-time training course have their salaries maintained during training. In addition to this, an allowance of £5 a week ($12) is paid to those who have to live away from home during training. All travelling expenses in connection with training are paid by the County Council, together with the cost of coming home once a term. An additional allowance of £30 ($72) a year is made towards the cost of any materials which may have to be purchased in connection with the training.

It is important to remember that if one is to train existing workers, they should be replaced by temporary employees while the workers are away on their training courses. While this has the effect of doubling the salary bill, it minimizes the burden which would have been carried by the remaining staff. It maintains a more stable environment in the school, and, in the experience of the Essex training center service, it has frequently been a means of testing out the suitability of temporary workers for permanent employment who can themselves be sponsored for training in the fullness of time. As a general rule, it is expected that staff sponsored for training by the Essex County Council should work for us for 2 years after training.

Five County mental health social work agencies (led, wherever possible, by a psychiatric social worker) offer advice to parents, are involved in public education programs, and form an invaluable link between the school or hostel and the home. It is outside the competence of the writer to discuss social work in detail, particularly as so much of the work surrounds the mentally ill as well as the mentally retarded. It is, however, true to say that both the range and quality of both care and training provided by any community will be modified by the quality of social service work offered to the mentally handicapped and their families.

Design of Training Centers

The County Architect's Department employs a full-time research worker whose task it is to assess the efficacy of the buildings and services supplied to the other departments of the County Council. Arrangements have been made, therefore, to incorporate the views of teachers and other interested parties in the design of an environment which actively promotes the opportunity for learning in retarded youngsters, which provides the staff with the range of facilities they require to pursue their various endeavours, and which, it is hoped, will give us some insight into the underlying principles surrounding the design of facilities for living and learning. It is anticipated that the next unit built in Essex will take the form of an experimental model which will have the dual function of forming part of our routine services while also offering teachers, administrators, planners, and research workers the opportunity to evaluate the effectiveness of current provisions for the retarded.

Educational Practice in Essex Training Centers

Junior Training Centers. An attempt is made to provide a range of activities which are emotionally, socially, and intellectually fulfilling and related to the child's developmental needs. The concept of formal group teaching has in large measure been surrendered in favor of the provision of an active environment in which learning based on experimentation is further reinforced by the teacher's guidance and participation.

It has been the experience of training centers in Essex--as in many other parts of Britain--that the implementation of an education program in which both teacher and pupils have the opportunity for flexibility and the chance to exploit a wide range of stimuli tends to promote the growth of language, ideas, and responsible behaviour in those children afforded these provisions.

In order to expand and develop potentially valuable situations, it has been suggested to the teachers in Essex that a formal class timetable should not be employed. Too often one sees a child purposefully involved in the manipulation of educational material, but the activity has to be curtailed because the timetable stipulates that another lesson should follow at a predetermined time. Learning in retarded children is ill-served when it is made subordinate to the demands of a clock.

One of the more unfortunate aspects of many educational programs for young retarded children is their heavy dependence on spoken language. The inability of many severely retarded youngsters to understand language adequately and verbalize effectively should lead us to question the validity of any curriculum which presumes the existence of linguistic skills when they do not, in fact, exist. In common with many schools for the severely retarded in Britain, the County Council of Essex attempts to provide a setting in which the child is offered involvement in a learning situation which is not necessarily dependent upon spoken language.

Adult Training Centers. In recent years, we have witnessed in Britain a very marked increase in the provision of industrial workshops for mentally handicapped adults. It was demonstrated that mentally handicapped people could undertake normal industrial tasks if these were offered under favorable conditions. Coupled with this realization, a significant body of opinion arose that it is good to treat the handicapped as if they were normal. It is normal to go to work in a factory; therefore we should provide factories for the subnormal. In making this assumption, however, people have overlooked the fact that in this world, that which is normal is not always natural, and that which is natural is not always desirable.

We have now arrived at a situation in Britain where far too many mentally handicapped adults attending adult training centers spend far too much time in the production of goods for local factories, and we seem content to overlook the fact that many of them earn less than a farm laborer in the middle of the last century.

The need for variety of experiences is just as strong in the mentally handicapped adult as in the retarded child. For trainees, industrial activity should not be permitted to assume a position disproportionate to its intrinsic value. In Essex, adult trainees are not expected to spend more than approximately half of their time in the performance of industrial tasks, and in order to support this policy, the adult training centers have been designed to accommodate a wide range of activities. These include industrial workshops and associated space; facilities for woodwork and other manual activities; domestic science rooms; a study/classroom associated with which is a small cubicle fitted with a one-way screen to provide facilities for any staff or research worker who may wish to undertake studies of individual trainees or for any trainees who may display the need for intensive teaching in a stimulus-reduced environment; an art studio offering facilities for pottery, painting, sculpture or any associated creative activity; a dining and recreation hall (a coffee bar is usually provided separately); and a general purpose room to allow for miscellaneous activities.

The provision of these facilities allows the trainees to involve themselves in a training scheme which offers not only training in a workshop situation but also a continuing program of intellectual and aesthetic stimulation. It is believed that there is a direct relationship between the level of functioning of the mentally handicapped and the range and nature of experiences afforded to them.

Transportation

The success of any system of daily care or training for the mentally handicapped will, in large measure, be determined by its accessibility. The cost of hired transport to serve the training centers in Essex is in excess of £40,000 a year ($96,000). While this may to some seem a high price to pay, one can only adopt the view that if one is going to provide a service to the mentally handicapped, one ought to ensure that it is used.

Research and Development

The old motto "No therapy without research--no research without therapy" is one which should never be forgotten by any community seeking to provide a comprehensive mental health or retardation service. In recognition of the need to support this principle, the County Council of Essex has sponsored the following studies which have either been completed or are in progress: methodological aspects of recording progress in the severely retarded; a study of the environmental influences on young retarded children at play; the development of a teaching machine for the investigation and promotion of concept formation; the development of a teaching machine for the promotion of social behavior in asocial retardates; a study of factors surrounding the early education of mentally handicapped children; an investigation of language in the context of the activity in which it is employed; a teaching film on play and development in retarded children as the first in a series of teaching films; a study of the prevalence of incontinence in retarded children; and an investigation of crying and laughing in retarded children. These projects have all been undertaken as part of the routine activities associated with service operations over the past 4 years. They were chosen because they were administratively simple, inexpensive, relevant to the development of facilities for the retarded, and capable of involving comparatively inexperienced workers without injuring the quality of the completed projects.

It is believed that with a reorientation of attitudes and a reorganization of existing manpower and facilities, the range of study into the field of mental retardation could be very considerably increased. Any mental health or retardation service which does not actively encourage original work must plead indifference or incompetence as the only adequate defense for its inertia.

General Considerations

In the last 20 years, we have witnessed in Britain a growing interest in the conditions which surround the mentally handicapped and their families. Mounting awareness of the poor quality of provision for the mentally retarded led to the development of a climate of opinion in which it became possible to plan for the needed services. Up to this time, most of the provision for the mentally handicapped was made available by institutions, and public expressions of private discontent naturally surrounded these institutions which had to deal with the bulk of the problem. As a result, many people have been vigorously pressing for the establishment of hostels in which the mentally subnormal can be cared for under better conditions than those associated with large institutions. It is important to realize, however, that for many retarded children, life in a twenty or thirty place hostel is still a very poor substitute indeed for a normal family life. While, as a nation, we are prepared to spend considerable sums of money on building and staffing expensive small units, we seem to have overlooked the possibility of recruiting, training and--if need be--housing a labor force of foster parents who would receive into care severely retarded children on a long-term or short-term basis.

If one accepts the fact that children maintain better progress in small units than in large ones, it seems remarkable that no adequate comparative studies on the effects of different patterns of care have been undertaken to assess the effectiveness of institution care, hostel care, and fostering in severely retarded children. In our anxiety to supplant the notion of caring for children in large institutions, we have made the tacit national decision to settle for hostel care without adequately investigating the alternative of fostering. Truly is it said that the good is the enemy of the best.

Any community seeking to establish services for the mentally retarded could usefully investigate the notion of recruiting and training a labor force of adequately paid foster parents. Such foster parents should be regarded as salaried, pensionable workers of the local authorities, and their endeavors should be subject to the supervision and support of these authorities.

The custom of paying inadequate allowances to foster parents inhibits many suitable married women from involving themselves in the field of child care. The idea is not infrequently propounded that foster parents should be motivated by love and not money. However laudable this may be, such expressions of piety make an unrealistic basis for the conduct of public service.

While it is evident that many retarded children would be unsuitable for placement in foster homes, it is believed that a significant proportion of children already in residential units would be more appropriately placed in foster homes. Apart from those cases needing active treatment, constant nursing, or the supervision of gross behavior disorders, it is difficult to argue a case for the institution placement of any mentally handicapped child. Too many mentally handicapped children are admitted to institutions because there is nowhere else to go. Simple amentia in children--like baldness and the common cold--seldom requires treatment in a hospital.

One of the criteria for fostering a child of school age should be the availability of a place in a day school and his suitability for attendance at such a school. Apart from other considerations, the companionship of school life is as essential to the retarded child as it is to his normal brothers and sisters, and should no such facilities be available, one may well consider residential placement to be an appropriate measure in such cases.

The development of residential services for both children and adults should be seen in the same context as the development of facilities for education, training, and recreation. The difficulties frequently associated with caring for handicapped children at home are significantly minimized if facilities for day training are provided. Not only does the child improve with education and training--thus making him more acceptable at home--but the mother is less tied to the house and consequently able to lead a fuller life herself.

Social workers are not infrequently made aware of the fact that the provision of day facilities tends to reduce the demand for residential care, and any community which does not offer extensive day facilities in concert with residential services is likely to acquire a distorted appraisal of the actual need for residential provision. The demand for residential placement is likely to be unnecessarily high if the provision of day school facilities is limited.

When dealing with the problem of the residential care of adults, one may well consider that their need is for a full, stimulating life offering employment at their own level, companionship, and the opportunity to involve themselves in a community on a long-term basis. It may well be that this need could be met in large measure by the institutions. With the growth of hostels for retarded adults, too many people are taking refuge in euphoria, and the smokescreen arising from the funeral pyre of the concept of adult institution care has obscured the fact that life in a small hostel can be just as dull and just as sterile as anywhere else.

At the present time in Britain, the Hospital Service is administratively separate from the local health and education services. This dichotomy makes it difficult for retarded residents in institutions to involve themselves in the community services, and there are many occasions when workers in the local health authorities find cases in their area who would be more appropriately placed as day residents in institutions. Many institution workers feel that they are often too far removed from the mainstream of the community's endeavor, and, conversely, a number of workers in local authorities would willingly involve themselves in the activities of the institution, but the administrative arrangements are rigged against mutual involvement.

The overwhelming majority of physicians in local authority mental health services are not able to prescribe treatment for the mentally handicapped, since this is done by the family physicians or the institutions. As a consequence of this, one finds that the nation has acquired a labor force of skilled workers whose terms of employment fail to exploit those very skills for which they were employed. The notion of training a man as a physician and then employing him on work which could be done by an administrator is wasteful, and for this reason the County Council of Essex arranged with the local Hospital Board that the County Psychiatrist should be employed jointly to work in the community mental health service and the local institution for the retarded.

While it has been suggested that only the severely handicapped child should be admitted to the institution, this carries with it the prospect of such children spending their lives in association with children suffering from a similar degree of handicap. In order to overcome the deleterious effect that this could well have on these children, it would be useful to investigate the concept of providing education and training for local authority and institution cases together. When one looks closely at the situation, there seems to be no adequate defense for separating the administration of the institutions from the community services. By uniting them both, severely handicapped children could be given the quality of residential care they require and still receive their education with other children. Adults in institutions, and those living at home, could be trained together either in the institution or out of it, and specialist personnel could apply themselves to the care and treatment of mental retardation in all its aspects and not be inhibited by the fact that the authority paying their salary was legally responsible for only one branch of the service.

Conclusion

Civilized conduct takes many forms and has many roots but has always one thing in common: it is tolerant of deviancy and protects the weak. Any community which seeks to promote the interests of the underprivileged will succeed only if it is united in its purpose and hungry for success; and as long as such books as this are necessary, the people we set out to serve will remain underprivileged.

Part VI: Model Service Models

Chapter 13

A Densely Populated Small State: Connecticut

M. Michael Klaber
University of Hartford

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A DENSELY POPULATED SMALL STATE: CONNECTICUT [1,2]

Services for the retarded in Connecticut have, for many years, enjoyed a well-deserved high reputation. Indeed, this state's program has been held up as a model worthy of emulation by others. There is a certain irony in this fact, for the only constant in Connecticut's services for the retarded is continuing experimentation and change. If there is one concept which underlies all developments here, it is the notion that today's services for the retarded are better than yesterday's, but inferior to tomorrow's. Therein lies Connecticut's greatest strength. The description of the system today (in early 1968) is therefore merely a static picture of a dynamic force, more analogous to a snapshot of a runner in motion than to an architectural blueprint of an imposing edifice. Even as these lines go to press, much will have changed already in the services, the techniques, and perhaps even "the philosophical approaches to this treatment of the retarded."

The Origins of the Connecticut Program

Current events are best understood in terms of their developmental history. An individual reflects the sum total of his cultural background, his social relationships, and his personal experiences. Governmental systems can only be understood in terms of the very special history each of them accumulates, and the specific circumstances which have led up to present practices. Since each system's background and setting are unique, it is impossible to transfer a working model from one locale to another without seriously considering the necessary changes associated with such a transfer.

Connecticut is a compact, densely populated state. In area it ranks forty-eight among the fifty states, yet it is fourth in population destiny. The people of Connecticut are generally affluent, ranking first in per capita personal income; they are relatively well educated, ranking in second place in the number of Ph.D.'s per million population and first in percentage of high school juniors scoring in the top 6 percent of those taking the National Merit Scholarship examinations. Manufacturing of sophisticated equipment (e.g., airplane engines, submarines)

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[1] This chapter was prepared with the assistance of Grant No. RD-1816-P from the Social and Adjustment Service of the U.S. Department of Health, Education, and Welfare.

[2] The work for this chapter could not have been completed without the full cooperation of the administrators, superintendents, and staff of Connecticut's facilities. Special acknowledgement is made to Mr. Bert W. Schmickel, Deputy Commissioner of Health in Connecticut. His guidance and support make it possible to delve into the diverse aspects of his program. Any distortions or misinterpretations found in the description of Connecticut's Program emanate from the author and are due to his own idiosyncracies.

and other industrial enterprises are the major source of the economic prosperity. Farming is relatively unimportant.[3]

While the overall economic and educational situation of the majority of the close to three million inhabitants of the state is a favorable one, the state has not escaped the problems of urban blight, regional unemployment, and individual hardship. The two major cities, Hartford and New Haven, have segregated ghetto areas, and some of the relatively remote rural sections have experienced considerable hardships due to the migration of indigenous industry to southern states.

Connecticut is proud of its New England heritage, and although its population is no longer predominantly Anglo-Saxon Protestant, it has retained the philosophy of individualism and self-reliance characteristic of its Puritan settlers. Town government is the mode of government. Politically, 169 independent towns maintain separate services for their inhabitants (including 169 separate school systems), and reliance on statewide social services is only reluctantly accepted as a necessary evil. The people in Connecticut want and enjoy close contact with their elected and appointed officials, and view their close relationship with government as an intimate right. This kind of setting, whatever its weaknesses, is especially receptive to the creation of regional, community-based services.

The origins of the current approach were, however, not dissimilar to national trends in mental retardation. During the early 1900's, mentally retarded and epileptic persons were segregated in a colony, and in 1917, Connecticut's first permanent "State Training School and Hospital" was established.[4] This facility was essentially a medically-oriented agency which offered medical treatment and custody on a thousand acre lot, located in a then most inaccessible area of eastern Connecticut near the town of Mansfield.

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[3] Figures derived from Connecticut Market Data, 1968, Connecticut Development Commission, State Office Bldg., Hartford, Connecticut.

[4] Connecticut had a privately supported institution since 1830, at which time a physician, Dr. Henry M. Knight, opened a small facility in his own home. In 1861, Dr. Knight founded a "School for Imbeciles" in Lakeville and incorporated it. Ownership of this facility was assumed by the state of Connecticut in 1913.

In 1907, the legislature called upon the governor to establish a "Colony for Epileptics." Evidently little came of this statue, and in 1909, the legislature enacted a statute calling for the establishment of a "Colony for the Treatment of Epileptics and Feebleminded" to be located in Mansfield. This facility was consolidated with the Lakeville institution and commenced operations in 1917 under the name of "The Mansfield State Training School and Hospital."

As the need for admission to this medical facility increased in the mid-1930's, the legislature nominated a commission to explore possible alternatives. One alternative was the expansion of bed space at the Mansfield facility. This tack would have been a relatively cheap one. Its major drawback was the great distance of this **hospital** from the population centers located in the western part of the state. Instead an alternate plan was considered, and it was decided that a second facility be erected. This new facility was to include in its catchment area thewestern half of the state (regardless of the type or nature of the retardation), while the Mansfield facility was to remain responsible for the eastern part of the state.

While in 1917 the most progressive thinkers conceptualized mental retardation treatment largely in medical terms, in 1937 a more pedagogical approach was emerging. The second facility to be erected in Connecticut was designed primarily for training and educational purposes. Its name was to be "training school," and not "hospital"; its philosophy was to be educational. The superintendent of the new Southbury Training School was to be an educator. Mr. Ernest Roselle was appointed to this post. Mr. Roselle believed in creating a setting which was to simulate home conditions as much as possible, and designed Southbury according to a "cottage plan" in which small units would house limited numbers of retarded youngsters, cared for by "cottage parents." These married couples were to regard the cottage residents as their extended family. In time, the Southbury Training School became to be regarded by many as the model facility among state-supported institutions in the United States.

While the two large facilities in the state stressed internal development (improved care, education, medical treatment, and additional bed space), in the 1950's, local pressures brought about the creation of new resources for the retarded outside the institutional settings. Community facilities began to be developed by local towns and by the parent groups without assistance from the state government. Special classes for educable and trainable retarded children were established in several of the more affluent school systems, sheltered workshops and day-care facilities sprouted here and there, and in 1953 the state legislature permitted reimbursement to towns who desired to serve retarded children through school systems, although education for the retarded was not yet mandatory.

It became increasingly apparent to the professionals in the field and to the parents that the existence of uncoordinated and autonomous approaches to retardation was not fulfilling the needs of the mentally retarded and that a reappraisal of the entire concept of service was in order. This re-thinking led to the current operational model in Connecticut: the regional program.

A Continuum of Services: the Regional Program

The basic assumption underlying the service approach to mentally retarded persons is rarely if ever expressed in Connecticut, yet it is implicit in the model and the philosophy: no institution can be as good as a good home. A corollary to this tenet is the operational maxim: let us do all we can to extend all services to the family so that retarded children and adults will remain in the community and in the home. This philosophy is not only based on ample research evidence but also, and perhaps mainly, on the basic human impulse to retain a child at his parents' side.

A basic shift in the philosophy of care necessitated a fundamental modification of administrative structure. Independently functioning, self-contained institutions led by autonomous superintendents, are incapable of establishing services which are responsive to community needs. A new authority with administrative powers was needed. This authority was established by statute in 1959 in the form of the Office of Mental Retardation.[5]

The Office of Mental Retardation

The Office of Mental Retardation was established within the framework of the Department of Health, which had hitherto been responsible for public health and maintained a number of chronic disease facilities. It was felt that the mentally retarded would fare better if not included with psychiatric facilities, which in Connecticut are the responsibility of the Department of Mental Health. The office was to be administered by a Deputy Commissioner who would act upon the advice of a "council on mental retardation." His task was clearly spelled out in the law: "he shall be responsible . . . for planning and developing a complete, comprehensive and integrated statewide program for the mentally retarded." His responsibilities also included the "coordination of the efforts of the Office of Mental Retardation with those of other state departments and agencies, municipal governments and private agencies concerned with and providing services for the mentally retarded." The intent of the statute was to lay a framework for a continuum of statewide services extended to all the mentally retarded and not only to those in residence at a state facility.[6]

The Administration of Connecticut's System

Emerson once said, "An institution is nothing but the lengthened shadow of one man." I am not sure that this aphorism reflects on an entire program of political action, but it certainly has some bearing on Connecticut's retardation model. Each of the institutions in this state bear unmistakably the mark of its original administrator, and the entire program the hallmark of its executive head.

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[5] At the same legislative session, a statute requiring public school systems to serve both educable and trainable retarded school-age children was passed.

[6] Quotations are from 1959 Statutes. See Appendix.

It appears that institutional systems are exceedingly slow to change and that it is therefore much easier to erect a new system to than to change an old one. In Connecticut, it was possible to fit the old and the new models into one framework. The first institution was medical in design (the Mansfield State Training School and Hospital); when its concept was superceded by a pedagogical model, it was not revamped, but instead another institution, the Southbury Training School, was established. Both facilities functioned together and served the state's population, though each was quite different in its conception.

Today, still another approach is taken: regional services based on a partnership between communities and state government. The two large institutions will, however, continue to function within the same framework as do the smaller centers. This is accomplished through relative regional autonomy, guided by central rules. In fact, the central office administers three separate but interdependent systems (see Fig. 1).

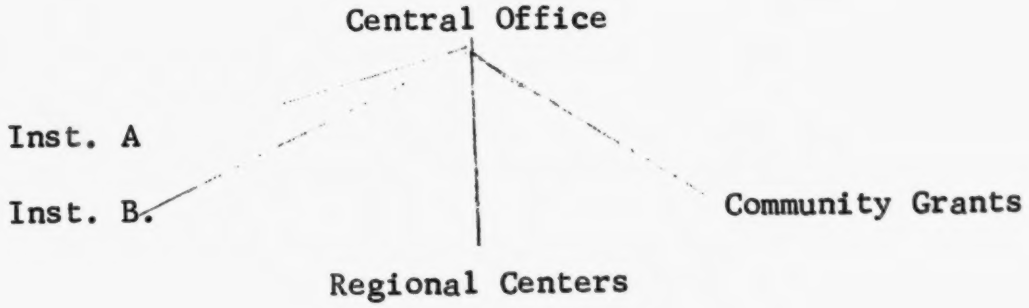


Figure 1

The superintendents of the two large (1,800 and 2,000+ beds respectively) facilities are directly responsible to the Deputy Commissioner. The regional centers, small in bed capacity (maxium 250 beds), are relatively less autonomous than the two large institutions. The third arm of the central office administers grants-in-aid to parent groups, clinics, and other community agencies.

The three arms of the system are thus independent of each other and permit a substantial amount of administrative flexibility. The actual table of organization is of course much more complex than indicated in Figure 1. It relates to many other state services within and without the State Department of Health. Citizen councils and advisory boards are active at all stages (See Fig. 2). It must be borne in mind, however, that people do not interact according to tables of organization, but in terms of personal interests, friendships, and idiosyncratic aversions. No sociogram of these real relationships is available to this author. The human qualities of interpersonal relationships, though uncharted determine the success or failure of a program.

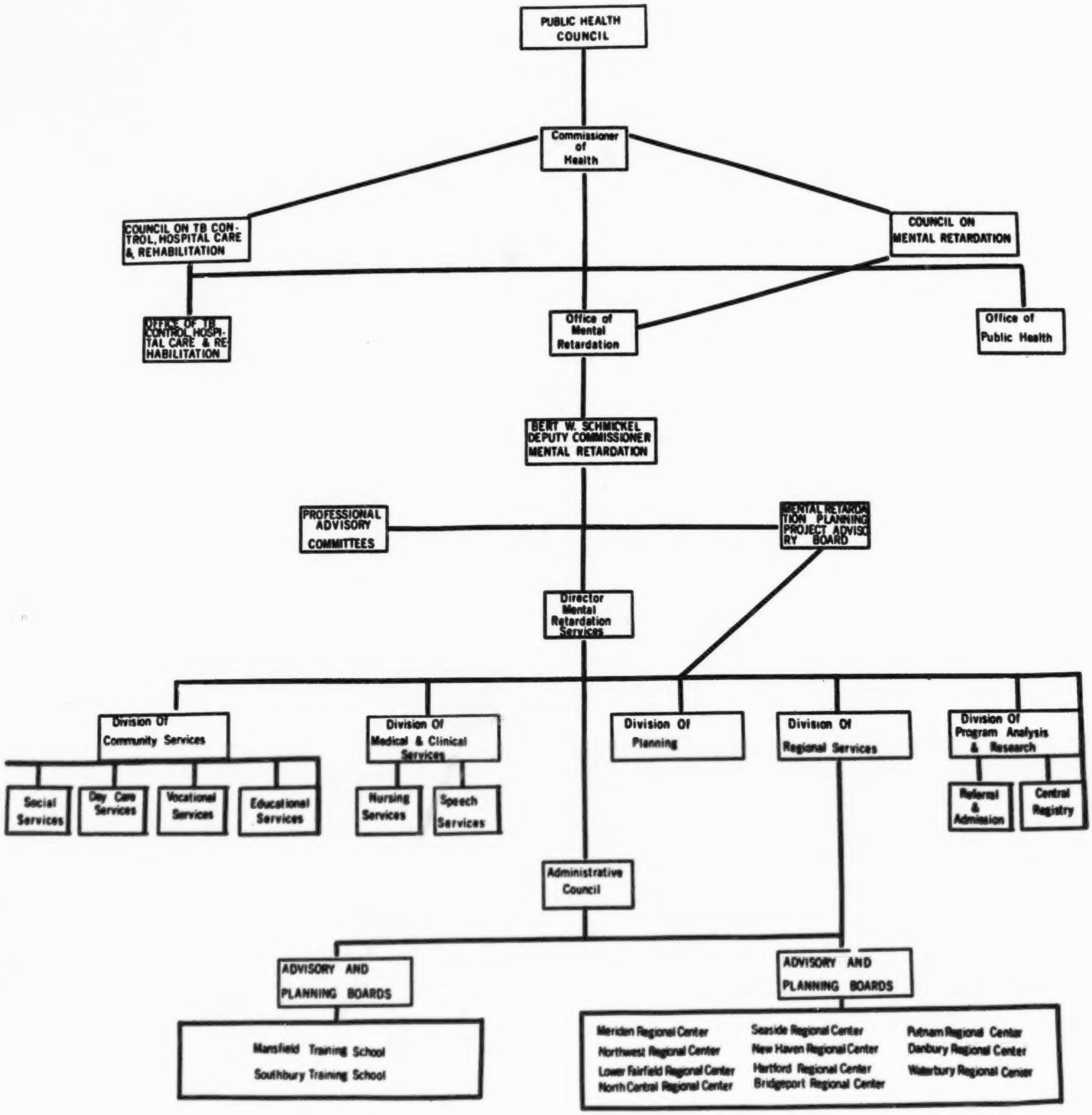

PUBLIC HEALTH COUNCIL
Commissioner of Health
COUNCIL ON TB CONTROL, HOSPITAL CARE & REHABILITATION
COUNCIL ON MENTAL RETARDATION
OFFICE OF TB CONTROL HOSPITAL CARE & REHABILITATION
Office of Mental Retardation
Office of Public Health
BERT W. SCHMICKEL DEPUTY COMMISSIONER MENTAL RETARDATION
PROFESSIONAL ADVISORY COMMITTEES
MENTAL RETARDATION PLANNING PROJECT ADVISORY BOARD
Director Mental Retardation Services
Division Of Community Services
Division Of Medical & Clinical Services
Division Of Planning
Division Of Regional Services
Division Of Program Analysis & Research
Social Services
Day Care Services
Vocational Services
Educational Services
Nursing Services
Speech Services
Referral & Admission
Central Registry
Administrative Council
ADVISORY AND PLANNING BOARDS
ADVISORY AND PLANNING BOARDS
Mansfield Training School
Southbury Training School
Meriden Regional Center
Northwest Regional Center
Lower Fairfield Regional Center
North Central Regional Center
Seaside Regional Center
New Haven Regional Center
Hartford Regional Center
Bridgeport Regional Center
Putnam Regional Center
Danbury Regional Center
Waterbury Regional Center

Figure 2

The Regional Centers

The main instrument of implementation of the Connecticut Program is to be the regional center. Whereas the state had been previously divided into two large segments which determined where a retardate would be institutionalized, it was reorganized into twelve regions for the purpose of services. The focal point of each one of these regions is such a center.

Based on the New England town government concept, the basic needs of an individual should be supplied through local (rather than central) services. Hence the primary task of a regional center is to stimulate new and to coordinate existing services for the retarded. It is based on the belief that each community has an obligation to provide for its citizens regardless of handicap. The provision of direct services to the retarded and their families, is seen as its secondary mission. In theory, a regional center could function in rented space in an office building, with its director and coordinators never giving direct assistance to retarded persons. In practice this has not worked out that way.

Realistic considerations, including financial necessities, dictated the creation of additional bed space. It was decided therefore that instead of developing a third large institution in Connecticut, an economical and reasonable alternative would be the creation of small residential facilities incorporated into the regional center design. These beds are available to the residents of each particular region and would be used strictly as just another service to the retarded, neither more nor less important than, let us say, day care.

The task of the regional director is to supply all necessary assistance to the parent so that he will be able to maintain his child at home and thus to permit as many retardates as possible to remain in the community. The retarded persons in residence will be integrated in their daily lives with the community at large as much as possible.

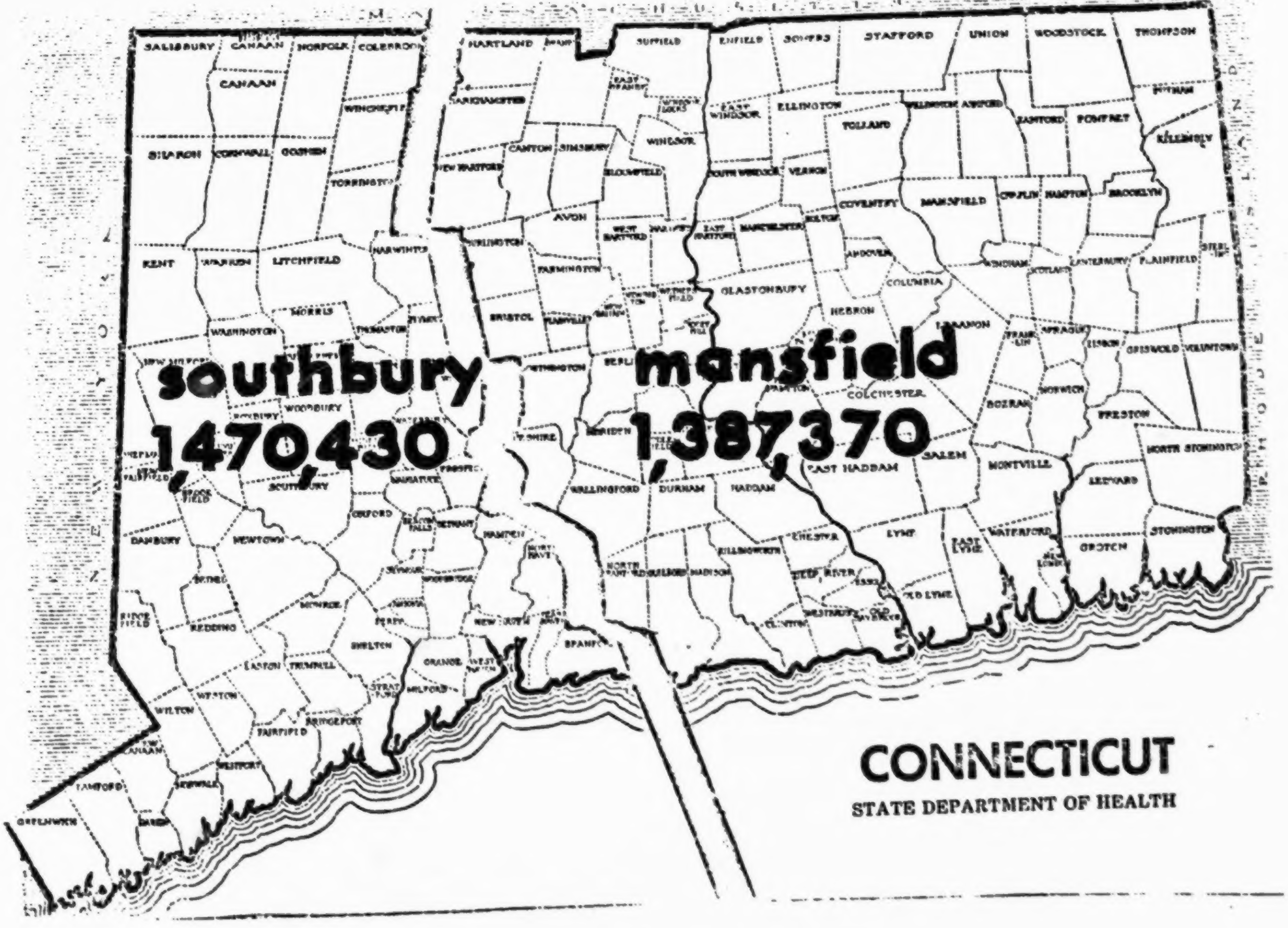
Although each of the centers differs from all the others, it is still possible to characterize their overall service philosophy through the programs they conduct. All centers are designed to maintain certain basic services, though some might offer additional ones.

Services to Retardates and their Families Living in the Community

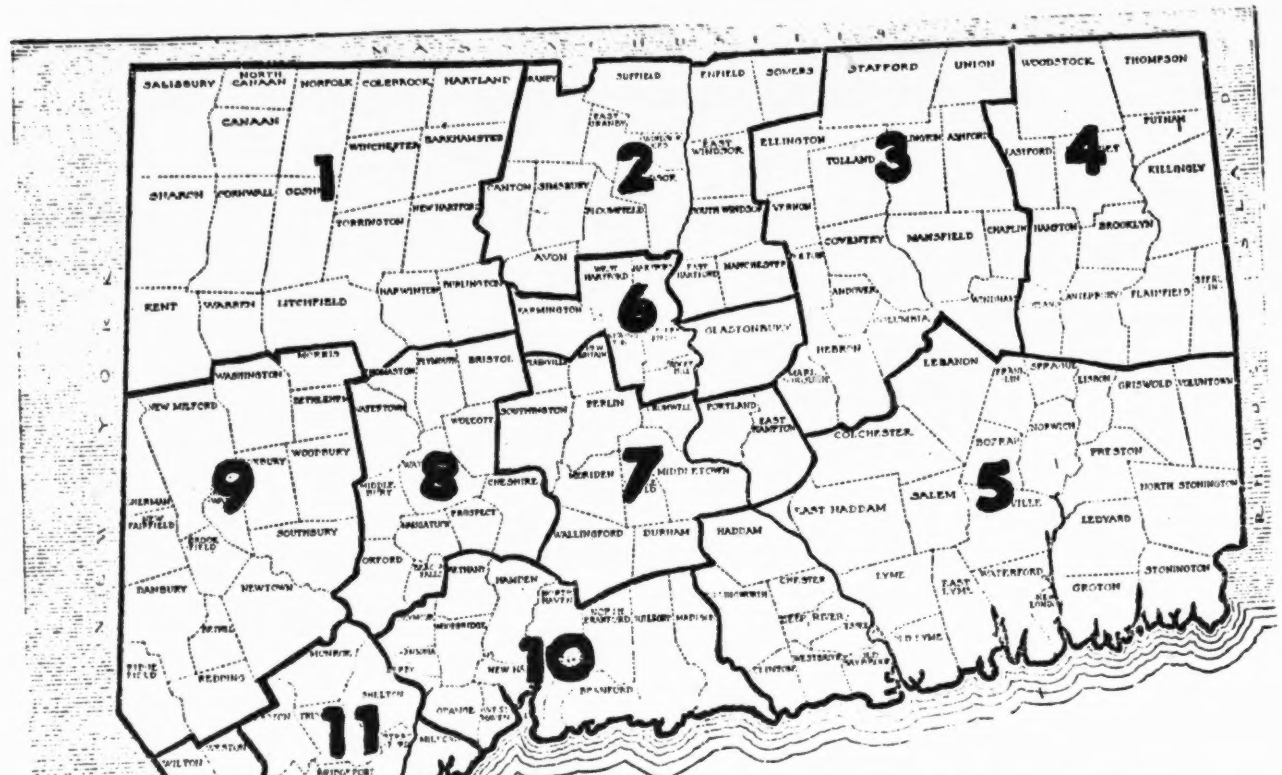
The basic services to the retarded rendered by the regional centers can be summed up as follows:

1. Day-care services for young, severely handicapped, or otherwise impaired children who are ineligible for public school special education classes. These services are rendered directly by the center, or parent groups who receive guidance from the center and financial support through the Office of Mental Retardation.

Figure 3


southbury
1,470,430
mansfield
1,387,370
CONNECTICUT
STATE DEPARTMENT OF HEALTH

Connecticut as served before regionalization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CONNECTICUT
STATE DEPARTMENT OF HEALTH
Office of Mental Retardation Regions

Regions as assigned to regional centers

This kind of service relieves the parent of the need for continuous supervision of the retarded youngster, and has thus permitted the return of women to the (tax paying) labor force. It also helps the child in preparing him for public school. Many of these youngsters are "graduating" to the special education classes within their communities.

2. Sheltered workshops for older retardates who have reached the maximum age for school attendance and can lead a productive, though non-competitive existence. These retarded men and women are an asset rather than a burden to their communities. Sheltered workshops receive supervision and guidance from the regional center and financial aid through the Office of Mental Retardation. Frequently, one such workshop is maintained on the grounds of the center and others at other localities within the region.

The problem of programming for the adult retardate is especially important. Since medical advances have increased the lifespan of retardates to near-normal length, most persons designated as being retarded are chronological adults. No program could therefore be comprehensive without offering extensive adult services.

3. Professional services to parents, children, and agencies. Frequently, guidance and information as to the availability of services are in demand. The regional center serves as central clearing house for all activities suitable for retardates, and its knowledge is available to all.

Diagnostic services are typically not rendered directly (whenever necessary, psychological and medical evaluations are conducted), but community clinics and hospitals are utilized. Connecticut is a small enough state to permit relatively easy access to such community facilities.

4. Recreational facilities for the retarded, especially for adolescents and adults, are usually scarce, though vitally necessary. The doors of the regional center are open to all in the evening and on weekends. The mere presence of a physical locale where retardates are welcome makes a great difference. Those retardates who live nearby take frequent advantage of this opportunity.

During the summer months, regional centers conduct special programs for all retardates, including those whose programs are provided by other agencies during the rest of the year. Typically, many schoolchildren are enrolled in this regional program.

A major task for recreation directors is the opening of general community recreational resources to the retarded. Community centers "Ys," youth organizations (Boy Scouts, Campfire Girls, etc.) have been alerted to the needs of retarded children and have responded well.

5. Educating the community is an intangible, though clearly basic necessity for the initiation of a successful regional program. The center can succeed only if retarded persons are seen by the population at large as potentially productive and intrinsically worthy individuals. Such attitudes are not established merely by lectures and talks to selected groups (PTAs, church groups, etc.), though these are also important, but primarily through demonstration in one's own agency.

The task of alerting the professional community to modern treatment philosophies in retardation is especially acute. Medical practitioners are frequently unaware of the educational and rehabilitative methods which have been developed for the retarded. Psychiatric clinics for children and adults have traditionally been uninvolved with the retarded and their families and are in need of guidance in their dealings with this population. This educational task of the center involves persistent and frequent joint case-conferences in which the professionals in the centers involve themselves with the professionals in the community. Potentially the community possesses all the resources for working with the retarded, but many decades of neglect have brought about persisting attitudes of hopelessness, which have led to the neglect of retardates and their families. Many years of patient education efforts through daily contacts with key professionals will be needed before a meaningful change in attitude will take place.

Services to Retardates in Residence

A different concept in residential services was evidently needed. Traditionally, admission to an institution to the retarded was considered an "all or none" affair: a child's admission constituted a significant break from his previous existence. Placement was considered to be a permanent solution to whatever problems had been presented by the youngster.

A new system of admissions was designed to meet immediate needs of children and parents. Instead of the permanent Probate Commitment which had been in effect hitherto, provisions for "voluntary" or "informal" admissions were made. This procedure permits short-term residence for retardates in state facilities with the guardianship remaining vested in the parent. Parents were now able to secure residence for reasons of acute family stress (e.g., birth or death of a family member), short-term residential evaluation of a retardate (e.g., suitability for semi-independent living), or even for a family vacation. Length of such a short-term admission can be from 24 hours to 6 months.

Special care is taken that residents of a regional center do not lose their ties with the community at large. Thus, as many services as possible are secured from the community, and the desirability of return to a child's own home, foster home, or hostel is stressed.

1. Educational services to the retarded residents of the center is rendered by the town in which the center is located. School-age children designated as being "educable" or "trainable" are sent to the local schools. The program is funded through a tutition plan in which the state reimburses the host town in full. Naturally, such an arrangement can operate only if the number of such students is kept within reasonable bounds. The small capacity of regional centers ensures the manageable size of these groups.

If a child is excluded from school for any reason, the center maintains its own facilities and the child is served by them. This service is also open to retarded community residents who have been excluded from public school for any reason.

Whenever a retarded child is excluded from a school system, the Office of Mental Retardation is notified by the State Department of Education. The Office in turn relays this information to the appropriate regional center whose task it is to investigate the case. Experience has shown that this investigation alone has reduced the number of school exclusions. If the child in question cannot be retained in school, the center will work out a plan for him which utilizes community and/or regional center resources.

2. Vocational habilitation for mildly and moderately retarded adolescents and adults is incorporated in the training department of the center. Attempts are made to place as many retardates in productive jobs as possible. Thus, the mildly retarded adults at the regional centers who assist in the maintenance of the institution and care of younger residents receive wages (at present, $10 a week). They are then assisted in spending their earnings judiciously.

In order to facilitate return to community living, some retardates are given the opportunity to reside in the center and to work at a job outside the center. They are then gradually encouraged to take up supervised, semi-independent residence at a carefully selected home. Those adults who are unlikely to achieve a level of functioning which would permit competitive employment are placed in sheltered workshop situations which will permit them to produce useful work according to thier ability. They, too, receive remuneration according to their ability.

3. Residential care represents the institution counterpart of parental care. In a family, however, two individuals expend considerable time and effort not only on the physical care of their offspring but also on their children's psychological and emotional development. In order to permit residents of regional centers to achieve reasonable development, they, too, must receive stimulation and support. To achieve this aim, regional centers use a variety of means: small unit size is conducive to individual interaction of aides and their charges;

hence, buildings are designed to have very small day rooms which can be attended to by one worker. Special efforts are made to bring people from the community in contact with individual residents. Federally financed programs have been particularly helpful in this area; foster grandparent programs, for example, permit the utilization of poor, elderly citizens for this kind of work.

Every effort is made to maintain contact with the child's family. Visiting hours are therefore completely open, with parents and friends being welcomed in the actual residential units.

4. Health services are not handled by a house staff, but are obtained through clinics and hospitals in the community. Medical practitioners are retained on a consulting basis. Typically, one physician comes regularly to the center once a week (though he is on call at all times), as does a local dentist. Whenever the need arises, medical specialists are called in. Hospitalization of a seriously ill resident occurs at the local hospital.

Such an arrangement has the dual advantage of using the best available medical personnel, while, at the same time, educating these professionals in the area of mental retardation. Many of these physicians return to their private practices with a changed outlook towards the problem of institutionalization.

5. Other services which require professional consultants (speech pathology, clinical psychology, physical and occupational therapy, etc.) may be rendered directly by the house staff, or, typically, a subprofessional, full-time staff member would be used. He in turn would consult with a full-trained professional who is primarily affiliated with another community agency. Thus, for example, a speech teacher with a bachelor's degree may be on the full-time staff, and consult with a speech pathologist who holds a Ph.D. degree and is affiliated with a local university.

The Service List

All the identified retarded persons in the region are known to the center whether or not they need service at a given time. The purpose of this list is to permit effective lifetime planning for the individual and his family. Thus, parents are urged to use the center's resources for crisis counseling (e.g., in case of parental illness, the retarded who has lost a job, etc.). The knowledge that a given agency, a known quantity, is interested in the retarded and his parents lends a sense of security to the family.

The service list aids in forestalling the sudden emergencies which have confronted the admission committees of the traditional facilities so frequently. The followup of the entire caseload permits methodical, lifetime help when needed, and thus strengthens the home in its ability to retain the retarded person.

The Role of the Training Schools

With the development of the regional centers the inevitable question arises as to the future role of the two larger facilities in the state system. Clearly, no one has suggested that they be relegated to a secondary position and be slighted in the newly developed regional system. Indeed, the question arises whether the regional centers are capable of performing services which are beyond the ken of the larger institutions. Theoretically, there is no community service performed by a regional center that could not be initiated by a training school. In practice, however, there are some significant inhibiting factors which mitigate against community involvement of these systems.

First, and perhaps most significant, is the inertia of systems. Whenever a large organization has been functioning for an extended period of time with clearly established goals and a philosophy of action, it is exceedingly difficult to reorient toward different ends. The philosophy of service of the large institutions typically saw residential care for the retarded as the most desirable service society can render for them. The staff took great pride in their ability to do more for the retarded than either the community or their parents were able to do. Thus, keeping a retarded child from entering an institution came to be regarded as an act of deprivation. The admission that institutionalization is in many situations an undesirable action is met by deeply ingrained, self-reinforcing psychological barriers at all staff levels.

There are still other variables which make it more difficult for traditional institutions to stimulate community action. One factor is the location of the institutions in sparsely populated rural areas of the state. Meaningful community involvement necessitates the physical location of offices and professional staff within the boundaries of population centers. The administrative tradition of state work creates an atmosphere in which employees are under the physical supervision of their superiors. Establishing semi-independent subunits of an administrative system necessitates a climate of trust and openness rarely found among training school administrators. Frequently, the climate of supervision makes such an arrangement psychologically too difficult for administrators.

Difficult as such arrangements might appear to be, they certainly are not impossible. In Connecticut the training schools have been able to develop some very effective community programs in spite of the problems involved. These programs have invariably involved utilization of new personnel consisting of persons whose professional careers were not inextricably bound to residential care. It is difficult to predict the future of the larger facilities. Probably they will have to continue to admit for residence those retardates who present the most difficult management problems within their communities. The larger institutions have already moved toward regional programs within their own areas. They have established sheltered workshops open to day students and hostels in neighboring cities. There is little doubt that these facilities will be expanded to accomodate those persons who lack family support, but can lead reasonably productive lives in the community.

In general, half-way houses, hostels, or community residences will become more important in the care of the elderly retardate. At present, there are about 100 older retardates in Connecticut residing privately owned and state-operated homes. Whether such an activity is supervised and initiated by a large institution or a regional center staff seems irrelevant. Ultimately there need be no difference in the kind of service rendered by the various facilities.

The most important impact of the regional centers on the larger institutions has been in terms of a changed philosophy. The emphasis has moved from custody to community service. In Connecticut, there had previously been an atmosphere of friendly competition between the two large institutions. Today this competition has been extended to the regional centers, so that each facility is competing for improved residential and community services. Thus, the creation of improved and better funded residential care within the centers creates an impetus for upgraded residential care in the large institutions.

How well Does the Connecticut Model Work in Practice--an Attempt at Evaluation

One of the most vexing aspects of socio-governmental systems is the difficulty in evaluating them. Unfortunately, we lack adequate tools to translate our behavioral constructs into a system of social accounting, analogous to financial accounting which reveals the economic efficiency of a business system. Even worse, the concept of self-evaluation is usually an afterthought, grafted onto an existing system, and rarely built into it from its inception. Connecticut's retardation program is no exception to this rule, and to date, even rudimentary data representing population movements are unavailable to the central office; only now, at the time of this writing, and 8 years after the creation of the Office of Mental Retardation, a Director of Program Analysis has been appointed whose task it is to collect such material.

Because of the lack of availability of central data, much of what is done in mental retardation in the United States (the problem is by no means confined to this state alone) is not fully known even to the persons responsible for the administration of these programs. Research delving into the daily operations of institutions is extremely scarce (a notable and interesting exception is Thormahlen's dissertation of training procedures in a California institution, 1965), as are inter-institutional comparisons. In order to close this gap, joint efforts between the office of Mental Retardation and the Department of Psychology of the University of Hartford have resulted in a series of investigations. Following a modest pilot study in 1964, a major project (of which this author is the director) was launched in 1965 with the aid of the Vocational Rehabilitation Administration. Included in this study were six residential facilities for the retarded, some of which were in Connecticut.

The detailed research design of the current study is not germane to this chapter, and will be made available in other forms (cf. Klaber, in press), but some of the findings are of general interest:

# Institutions differ significantly in the quality of care their residents receive, even with similar per capita expenditure.

# Effective institutions promote general adjustment, self-sufficiency, and intellectual development among their residents. Ineffective institutions lag in these respects.

# Effective institutions are characterized by a high amount of social interactions between the retarded residents and nonretarded adults. These interactions are facilitated by the presence of volunteers, professionals, and other nonattendant personnel on the wards.

# Absolute unit size is more important than the overall personnel-to-resident ratio. (Thus, for example, ten units of ten residents, each with one child-care worker, is more conducive to social interactions than one hundred residents to which ten workers are assigned.)

# Within a reasonable radius (100 miles), parental visits are determined by the effectiveness of the institution, and not by the distance to the parental home.

# In-service training procedures did not have an observable effect on aide-behavior, as noted in the six institutions studied. Thormahlen also was unable to ascribe any direct relationship between training of attendants and their job performance in a California institution (Thormahlen, 1965, p. 62).

# The architecture of the institution was associated with the nature and amount of programming promoting adjustment and self-sufficiency, and played a significant role in the interpersonal contacts of residents. The more "efficient" the floor plan in terms of factory models (e.g., large rooms with glass-enclosed aide stations, rows of toilet commodes, etc.), the less likely an individual resident is to interact with a nonretarded adult.

# Special programs affect ward personnel if they are conducted in the building where the residents are housed, but have no effect on their behavior if conducted elsewhere.

The foregoing examples bring to mind some immediate recommendations which might be made from applied research. The Office of Mental Retardation has kept in constant touch with our research unit and has made arrangements to upgrade residential care in accord with our findings.

The Personnel Problem

The lack of professional personnel is a national problem to which Connecticut is not immune. In theory, the regional approach brings larger numbers of professionals to the community in the service of the retarded. In practice, there has been a dearth of highly trained individuals. Except for persons in the field of special education, there are insufficient numbers of physicians, dentists, psychologists, occupational and physical therapists, nurses, social workers, and other skilled professionals available. Even the central office lacks adequately trained personnel, and positions of consultants in medicine, social work, education, and speech services were either not made available by the State Personnel Department or remain open because of lack of qualified applicants. The situation is even more critical at the local level where regional centers lack adequate personnel to carry out their mission.

The problem is not simply one of salary, though it undoubtedly plays a role. The core of the personnel problem seems to inhere in the rigidities imposed by civil service. In a situation where an applicant's market prevails, state personnel practices simply do not meet the conditions which render such service sufficiently attractive to highly skilled personnel.

The prevailing seniority system frequently imposes relatively poorly trained department heads on young, better trained, vigorous new workers. The ensuing friction usually leads to the resignation of the junior professional. A survey of professionals who had left institutional work suggested to us that the milieu offered to the young graduate was not congruent with the expectations developed during his university training.

Problems of State Government

The framework of governmental operations imposes other difficulties on the retardation system. In Connecticut, the legislature meets only every 2 years, so that budgets have to be prepared far in advance. It happens frequently that funds become available after the needs have changed. Worse, still, is the delay in building facilities. Long lapses often occur between the legislative approval of a facility and the time the facility commences operations. This time lapse between the conception of an idea and its execution can prove exceedingly frustrating to many persons.

To date, only three regional centers are in full operation. Several others are operative on a nonresident basis.[7] One, Seaside, has been in operation since 1960 and thus furnishes us with the only data to evaluate the regional center's effectiveness. So far, the concept has worked well. Objective data show that Seaside's residents are developing at a more accelerated rate than those in large institutions. The waiting list is extremely small, and many residents have been returned to the community.

A breakdown of a followup of consecutive residential admissions to Seaside is illuminating. Current capacity is 240 beds. So far, there have been 443 individuals admitted. Eighty-four youngsters (19%) returned to their own home, 41 were placed in independent work situations, 15 in boarding homes, and 4 in foster homes. Fully one-third (33%) of all persons admitted have thus been returned to the community. This percentage is probably much higher than for any other public facility in this country. However, the final effectiveness of Seaside's ability to habilitate retarded persons will only be determined over the years as its long-term residential population ages. Pressures for admissions appear to have decreased, and currently a waiting list of only 15 cases is kept on the books.

The two other regional centers have not been in operation long enough (since 1966 and 1967 respectively) and their capacity is as yet so small (96 beds in each) that not much information has been accumulated. Yet, although their residential space is relatively small, each of them is serving several hundred retardates through their varied nonresidential facilities. Through these services, pressure for institituionalization of retardates appears to have diminished.

As each of the centers is assuming its individual identity, certain individual differences emerge. Thus, for example, the New Haven Regional Center has been able to create an important link with Yale University. The psycho-educational clinic under the direction of Professor Seymour B. Sarason is supplying psychological services to the center, while the center in turn has opened its administrative and care facilities to the clinic. Such mutually beneficial arrangements can be shown to be of major importance to the management of retardation as well as to the development of new directions in general social science (Sarason, et al., 1966). The Hartford Regional Center, to cite another example, is much more self-contained and has developed a program approach of its own. It has developed a program for training health aids from poverty areas in which unemployed persons are trained for work in convalescent homes and hospitals as well as in retardation facilities.

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[7] This is not to imply that the nonresidential services are without merit. Quite the contrary, substantial parent counseling, day-care, and social casework services are rendered by most regional centers almost immediately after authorization.

Whether or not the semi-autonomous development of each regional center is the most effective form of administration is as yet a moot point. Only long-term assessments will show if a more uniform, centrally imposed structure would have produced more desirable results.

In terms of daily activities, regional centers double to triple their services to nonresidents in relation to their resident population. Thus, a center with one hundred residents would typically serve an additional one or two hundred retardates living in the community. These activities supplement the already existing services and are not designed to take their place. The major populations served on a daily basis are children who were excluded from school and adults without programs in the community. Indirectly, many additional families are served through counseling, auxiliary recreation programs, etc.

The staffing patterns of the centers are somewhat flexible, but the following table of organization of the New Haven Center is fairly representative.

It is the impression of persons involved in the Connecticut program that these services are not only more humane but probably also cheaper in the long run. In the absence of cost accounting in the state facilities, this statement cannot be made with certainty, yet it seems reasonable to assert that even relatively expensive day services for any given individual cost only a fraction of the finances required for adequate round-the-clock care.

No discussion of a contemporary American retardation program would do justice to the subject without mentioning an all-important yet seldom alluded to factor: the ability to obtain and administer federal grants-in-aid. Many special projects serving the needs of the retarded are funded exclusively or partially by such grants. A great deal of know-how is necessary to ferret out the existence of such grants from the maze of federal bureaus, agencies, and divisions. An even greater expertise is required in the preparation of grant applications which meet the necessary requirements of the potential granting agency. Some of Connecticut's facilities have been more successful in obtaining substantial federal support than others. Consequently, a certain unevenness in the development of similar institutions is apparent. At this time, it is extremely difficult to point out the specifics as to the reasons why one administrator is more capable in developing acceptable proposals than another, yet in some ways certain agencies are much better equipped to attract and retain grant generating personnel. When this occurs, certain programs which ordinarily would be within the region of a given center will be administered by another facility.

There is little doubt that ultimately such programs will be coordinated and supervised by the Central Office. That this has not yet been done reflects the rapid growth of the program and the inevitable loose ends which are unavoidable side effects of such expansion.

NEW HAVEN REGIONAL CENTER

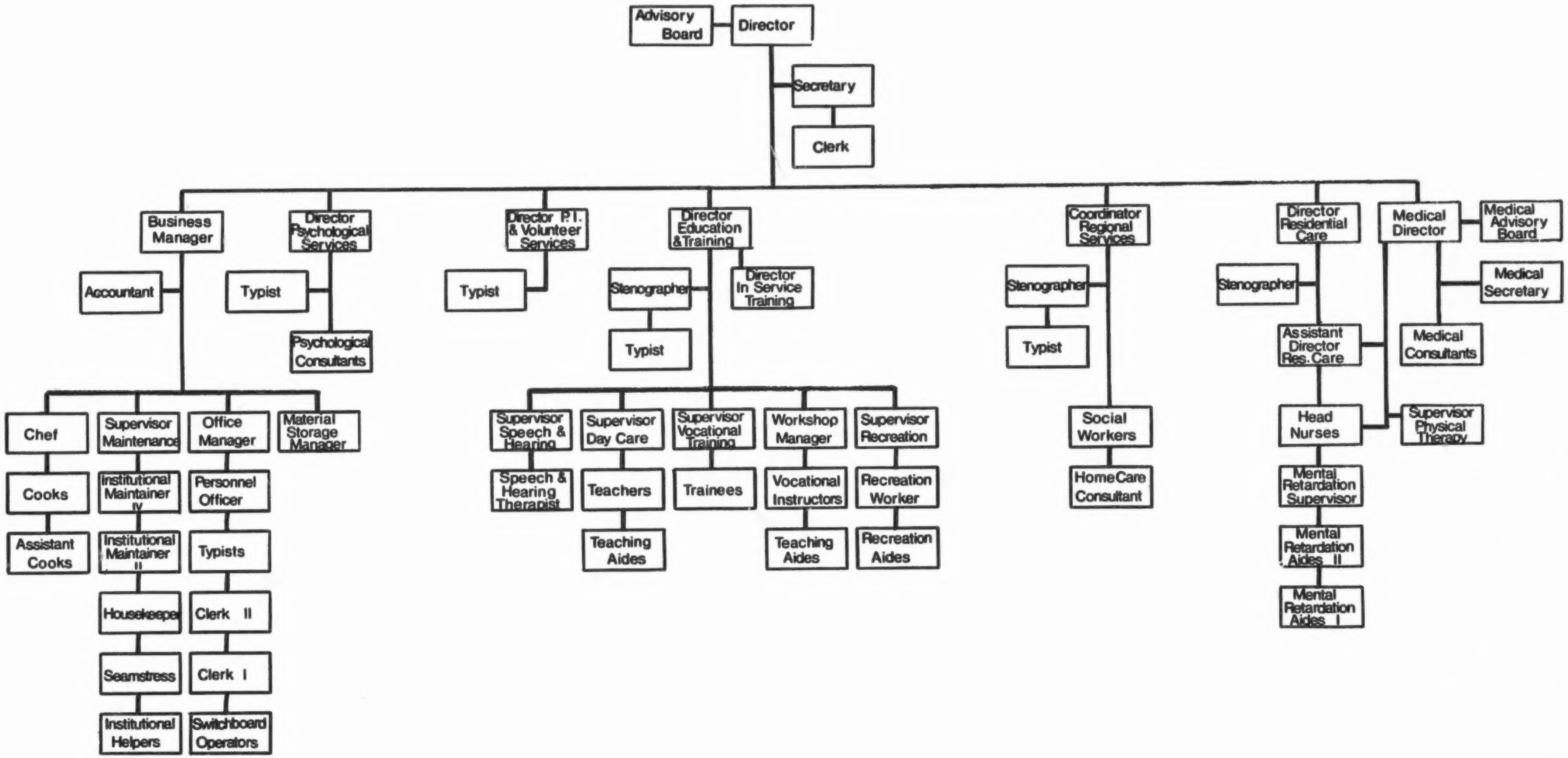
Advisory Board
Director
Secretary
Clerk
Business Manager
Accountant
Chef
Cooks
Assistant Cooks
Supervisor Maintenance
Institutional Maintainer IV
Institutional Maintainer II
Housekeeper
Seamstress
Institutional Helpers
Office Manager
Personnel Officer
Typists
Clerk II
Clerk I
Switchboard Operators
Material Storage Manager
Director Psychological Services
Typist
Psychological Consultants
Director P.I. & Volunteer Services
Typist
Director Education &Training
Stenographer
Typist
Director In Service Training
Supervisor Speech & Hearing
Speech & Hearing Therapist
Supervisor Day Care
Teachers
Teaching Aides
Supervisor Vocational Training
Trainees
Workshop Manager
Vocational Instructors
Teaching Aides
Supervisor Recreation
Recreation Worker
Recreation Aides
Coordinator Regional Services
Stenographer
Typist
Social Workers
HomeCare Consultant
Director Residential Care
Stenographer
Assistant Director Res. Care
Head Nurses
Mental Retardation Supervisor
Mental Retardation Aides II
Mental Retardation Aides I
Medical Director
Medical Advisory Board
Medical Secretary
Medical Consultants
Supervisor Physical Therapy

Figure 4

Planning for the Future

The Connecticut program would be ineffective indeed if it were to adhere rigidly to one mold. As new needs arise, existing facilities and personnel gain experience, new modes of thought are pursued. It would be a mistake to assume that current plans simply call for a proliferation of regional centers. Changes are constantly made. Thus, for example, the newest architectural plans call for the smallest possible "living units" rather than for larger structures.

Figure 5 represents a floor plan for a newly designed cottage for 18 mentally retarded persons. It was planned to provide maximum flexibility by making three living units, or "clusters," as self-contained as possible.

By providing separate living room space (LR) and a bathroom for each of the three bedrooms (BR), it will be possible to house three distinct groups, e.g., adults, adolescents, or young children. The cottage is currently planned to serve mild and moderately retarded persons, but could also be used for severely retarded ambulatory residents. With some modifications, profoundly retarded and physically handicapped persons could also be served by the same structure. The redesign builds in an appropriate ratio of personnel to residents by requiring the presence of at least one child-care worker in each cluster.

Even more advanced is the possibility of creating regional centers to serve all handicapped persons. Discussions are now under way to establish such an experimental center in which services for all the handicapped can be coordinated. Perhaps it will be possible to utilize specialized services in a more effective manner in this fashion.

Since Connecticut's state plan for the retarded, significantly entitled Miles to Go, was published (March 1966), many of its far-reaching recommendations have been carried out, yet it is already evident that a permanent planning office is essential to the continued improvement of services, and has been incorporated into the central office's table of organization.

An Overview

Services to the retarded are seen in Connecticut as belonging in a "continuum of care" which allows fluidity of movement of the individual from one type of service to another. The coordination of these services is the responsibility of the Office of Mental Retardation. This approach is implemented through a series of regional centers whose orientation is towards community rather than residential services. Side by side with the regional centers, the older, larger, residential institutions continue to serve the retarded, while state grants stimulate parent and community services.

NEW HAVEN REGIONAL CENTER
Residential Cottage

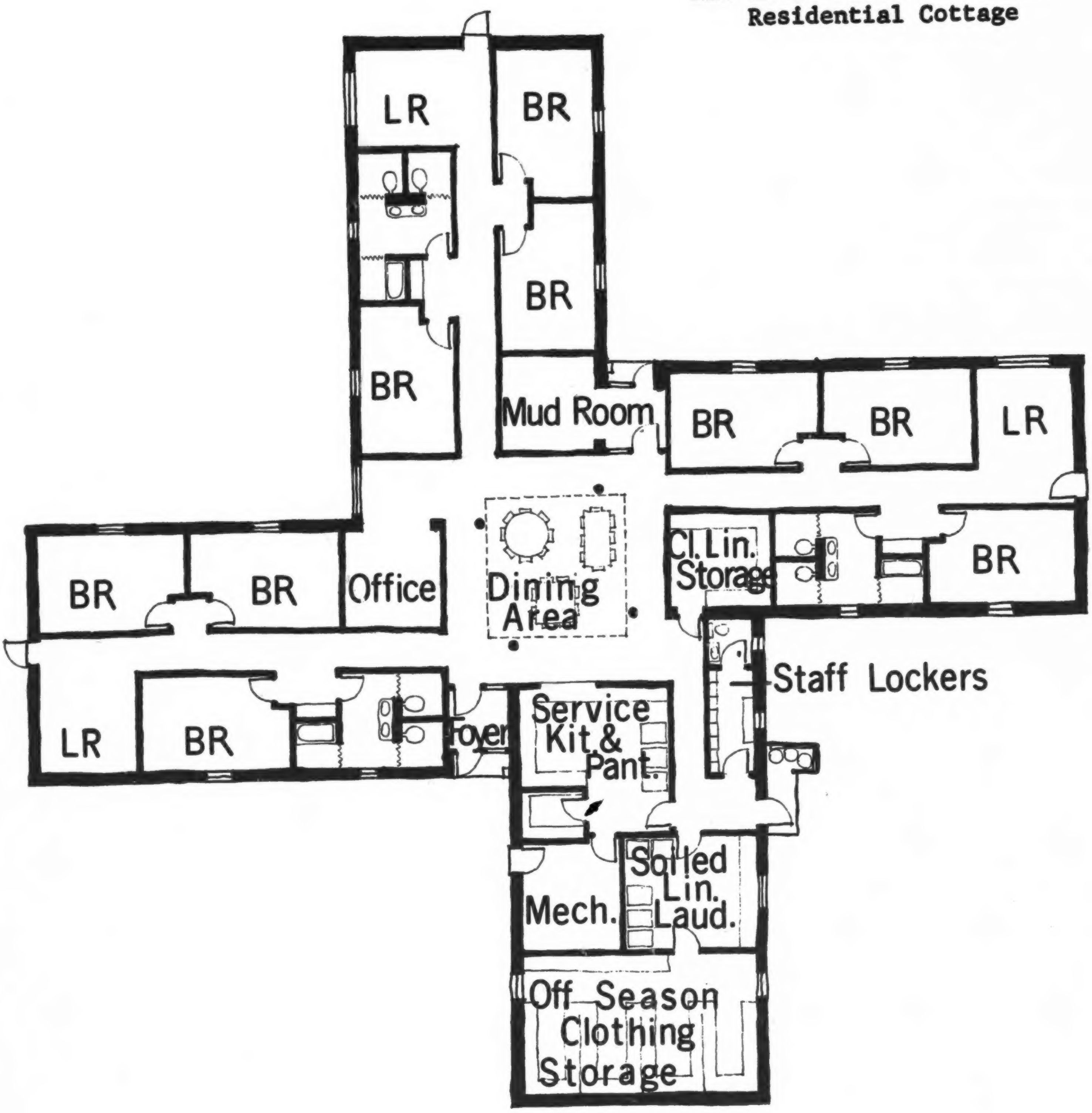
LR
BR
BR
BR
Mud Room
BR
BR
LR
BR
BR
Office
Dining Area
Cl. Lin. Storage
BR
LR
BR
Foyer
Service Kit & Pant.
Staff Lockers
Soiled Lin. Laud.
Mech.
Off Season Clothing Storage

Figure 5

The entire program is based on a conviction that the needs of all the retarded from cradle to grave can best be met through the cooperation and coordinated efforts of community agencies, professionals, and others, in partnership with state programs. No longer is the state residential program a separate, isolated last or only resort. Residential care is seen as an integrated part of the complete array of services which may be beneficial to retarded children and adults during some period of their lifetime.

While it is still too early to evaluate the effectiveness of the Connecticut model, preliminary findings of studies of residential care suggest that regional centers return a much larger proportion of admissions to the community than do larger, more isolated facilities. The development of children who reside in the small centers has been shown to be more accelerated than that of children cared for in large facilities. Waiting lists have been small, and community responses most favorable.

The Connecticut program is conceived along dynamic, ever-changing lines, so that it will be capable of responding to change. Indeed, it is hoped that the model will supersede itself when the time comes.

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APPENDIX

(1963 Supplement to the General Statutes)

Sec. 19-4c. Office of mental retardation. Deputy Commissioner. The office of mental retardation, with the advice of a council on mental retardation, shall be responsible for the planning, development and administration of a complete, comprehensive and integrated state-wide program for the mentally retarded. The office of mental retardation shall be under the supervision of a deputy commissioner on mental retardation, who shall be appointed by the commissioner of health on recommendation of the council on mental retardation and may be removed by the commissioner after consultation with the council. The deputy commissioner shall be a person whose background, training, education and experience qualify him to administer the care, training, education, treatment and custody of mentally retarded and epileptic persons. He shall be responsible, under the general superivision of the commissioner and with the advice of the council, for planning and developing a complete, comprehensive and integrated state-wide program for the mentally retarded; for the implementation of said program; and for the coordination of the efforts of the office of mental retardation with those of other state departments and agencies, municipal governments and private agencies concerned with and providing services for the mentally retarded. He shall be responsible for the administration and operation of the state training schools, and all state-operated community and residential facilities established for the diagnosis, care and training of the retarded. He shall be responsible for establishing standards, providing technical assistance and exercising the requisite supervision of all state-supported diagnostic facilities, day-care centers, habilitation centers, sheltered workshops, boarding homes and other facilities for the mentally retarded. He shall stimulate research by public and private agencies, institutions of higher learning and hospitals, in the interest of the elimination and amelioration of retardation and care and training of the retarded. He shall be responsible for the development of criteria as to the elibility of any retarded person for residential care in any public or state-support private institution and, after considering the recommendation of a properly designated diagnostic agency, may assign such person to a public or state-supported private institution. He may transfer such persons from one institution to another when necessary and desirable for their welfare. (1959, P.A. 148, S.22.) (See Ch. 305, part III.) (Repealed P.A. 377, Sec. 3., June 1963.)

Sec. 17-175a. Voluntary admission to facility for mentally retarded persons. Termination of admission. Any person who has been a resident of Connecticut for the two-year period immediately preceding an application made by him or on his behalf under the provisions of this section and section 17-175b, and who is, or appears to be, or believes himself to be, mentally retarded or epileptic but not mentally ill, may apply, in writing, to the deputy commissioner on mental retardation, on a form prescribed by said deputy commissioner, for admission to any state school, diagnostic center or other institution having facilities for mentally retarded or epileptic persons. Such application shall be accompanied by a certificate, signed by a physician licensed to practice medicine in the state, that such person is suitable for admission to such school, center or institution, and by a psychological diagnostic evaluation provided by a psychologist certified under the provisions of chapter 383 when such applicant has the physical and mental capacity for such evaluation. The application for such person, if such person is a minor, may be made by a parent, guardian of the person of, or person having custody of, such minor or, if such person is an adult incompetent, may be made by the conservator or person having custody of such incompetent. The deputy commissioner shall approve any such application for admission if the person on whose behalf application is made is suitable for admission to such school, center or institution and facilities to accommodate him are available and may terminate such admission at any time when he feels such person will not profit from a further stay. (1961, P.A. 260, S. 1; 1963, P.A. 377, S. 1.)

Part VII: Toward New Service Concepts

Chapter 14

The Creation of Settings

Seymour B. Sarason
Yale University

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THE CREATION OF SETTINGS[1]

Introduction

This paper is an attempt to discuss two questions: (1) How do people go about creating new settings (I shall be using the terms settings, programs, organizations, institutions interchangeably)? (2) What body of theory and practice is available as guidelines for those who have the responsibility of creating settings? Although I shall be discussing these questions within the narrow context of certain aspects of the mental retardation field, it is my hope to demonstrate in later publications the generality of the problem in as phenotypically diverse activities as art, research, industry, as well as social-political movements which have as an aim the creation of new institutions (in the sociological sense). Despite the obvious and many ways in which the American constitutional convention, the Russian revolution, a new business, a new university, a new hospital or clinic, or new mental retardation service differ, they involve the human mind in the production of end products which will be consistent with original purposes. That is to say, these end products are supposed to have a meaning and structure which are not defeating the purposes of the creators or the interests of those for whom the end products were developed. When in his pioneering book in 1860 on the Italian Renaissance Burckhardt entitled the first chapter "The State As a Work of Art"--meaning it is the product of processes "of reflection and calculation"--he was, I think, recognizing that the creation of settings has kinship to many other types of important human activity from which we have much to learn.

When one looks over the history of human service fields, such as mental health and mental retardation, one sees time and again how they have changed as a function of a new conception, or theory, or technique (Sarason and Doris, 1969). What I aim to do in this paper is twofold: to examine some of the consequences of these changes, and then to discuss the creation of settings which I consider to be a crucial problem with which human service fields will have to grapple over the coming decades. I fully realize the two dangers involved in such a discussion: one of them stems from any attempt to attain perspective on the present, and the other inheres in any attempt to read the future.

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[1] This paper is based on two previous ones. The first paper, "The Creation of Settings," was prepared for a book, The Yale Psycho-Educational Clinic: Papers and Research Studies, edited by Dr. Frances Kaplan and myself and to be published by the Massachusetts State Department of Mental Health. The second paper, "The Creation of Settings: the Beginning Context," was prepared for presentation at the Kennedy Foundation Scientific Meeting in Chicago in 1968. At the request of the editors of the present volume those two were combined, revised, and elaborated upon for publication here.

The Significance of the Rate of Creation of Settings

I am quite sure that I am not far wrong when I say that in the past two decades more new settings have been created than in the entire history of the human race. For example, when the Headstart legislation was implemented it meant that several thousand discrete settings were to be created, i.e., in each setting a group of people (children and adults) were to be brought together in sustained relationships to meet certain objectives. When one considers that Headstart is but one of thousands of federal programs--in addition to those created by states, communities, industry, etc.--it is clear that we are dealing with a fantastic rate of setting creation. In addition, one must keep in mind that within our larger institutions and organizations (e.g., hospitals, schools, universities) new programs are constantly being implemented, programs which result in grouping or regrouping of individuals into new and presumably enduring relationships for the attainment of stated objectives. Faced with the task of creating a setting, particularly one devoted to human service, what theory and experience are available as guidelines? The answer, unfortunately, is very clear. Existing psychological theories--be they primarily individual or social psychological in nature or emphasis--do not address themselves to the problem of the creation of settings. There is an ever-growing body of theory and observation on "sick" settings--which in a few years will probably be equal in bulk to that of "sick" individuals--but little or nothing on the creation of healthy settings. The problem will not be clarified because of the tendency, understandable in clinicians, to focus on, or to be called to, the malfunctioning setting.

Within the past decades, few fields rival mental subnormality in the rate of setting creation. It is neither to disparage these efforts nor to assume the role of prophet of gloom that I maintain that these new developments may in general miss their intended goals--not for a lack of appropriate motivation or financial resources but rather because these new programs or settings do not reflect an explicit awareness that the creation of a setting involves problems and requires a way of thinking not contained in the implicit or explicit theories which ordinarily guide us.

The problem would be difficult enough if only new settings were involved. However, as Blatt and Kaplan (1967) demonstrated in their photographic essay Christmas in Purgatory, we are also faced with the problem of how to change settings which no longer are consistent with their stated purposes and, let us not forget, debasing of all concerned.

In my opinion, the major significance of their work is the force it gives to the question: why do programs and settings fail? The question goes far beyond the confines of mental subnormality. Elsewhere (Sarason, Levine, Goldenberg, Cherlin, and Bennett, 1966) my colleagues and I have indicated that the question is central both to our understanding of professional as well as organizational failure:

> In an article we consider to be among his most important statements--an article not read and reread with the frequency it merits--Freud takes up the problem of how the analyst must protect himself against tendencies that rigidify and insidiously damage his outlook and practices--considerations that led Freud to suggest that analysis ought to be re-analyzed every several years. His discussion is, in our opinion, highly relevant to the problems of social organizations and their tendency to be smug about what they are doing, and, as a consequence, to be blind to the fact that they are no longer responsive and sensitive to their original goals. Gardner has succinctly and beautifully put the same problem in terms of organizations and is contained in his concept of "educating for renewal":
>
> "I have collected a great many examples of organizations or institutions that have fallen on evil days because of their failure to renew themselves. And I want to place before you two curious facts that I draw from those examples. First, I haven't yet encountered an organization or institution that wanted to go to seed or wanted to fall behind in the parade. Second, in every case of organizational decline that I know anything about, there were ample warning signals long before trouble struck. And I don't mean warning signals that only a Monday-morning quarterback could discern. I mean that before trouble struck there were observers who had correctly diagnosed the difficulties to come.
>
> "Now if there are plenty of warning signals, and if no organization really wants to go to seed, why does it ever happen? The answer is obvious: eyes that see not, ears that hear not, minds that deny the evidence before them. When organizations are not meeting the challenge of change, it is as a rule not because they can't solve their problems but because they won't see their problems; not because they don't know their faults, but because they rationalize them as virtues or necessities."

The Empirical and Theoretical Problem

How do people go about creating settings? In light of the lack of relevant theory and description, a number of us at the Psycho-Educational

Clinic have taken advantage of several opportunities to observe and participate in the process. The first opportunity is very partially described in our book on the Yale Psycho-Educational Clinic (Sarason, et al., 1966). The second, and a far more significant and sophisticated attempt, involved Dr. Ira Goldenberg's assuming the responsibility for organizing and developing a Residential Youth Center for inner city boys between the ages of 16 and 21. The third opportunity--involving Dr. Frances Kaplan, George Zitney, and myself--is very recent and concerns an institution for the mentally retarded which will not be a physical reality for at least 2 years.

Obviously, it will be some time before we will be able to organize and present our thoughts, experiences, and data in coherent form. But certain general statements can already be made:

1. In creating a setting, the person or persons with responsibility quickly became overwhelmed by two related, strong feelings: first, the problem is far more difficult than they imagined, and second, that they have no explicit guidelines for determining what they will do, the sequence in which it might be done, how to anticipate problems, etc.[2] This becomes most revealing when the person or persons with responsibility are professional individuals with a demonstrated competence in dealing with the dyadic or small groups therapeutic situation. When handling individual problems they are relatively at ease. They have a feeling of security about what they are doing, why they are doing it, and how it is likely to come out. They have wedded theory and technology which, despite its shortcomings, serves as a psychological map. Faced with the task of creating a setting, they tend to feel as if they were alone in a small boat on uncharted seas, with a cloud cover obscuring the stars, possessing no reliable compass--and worried lest the frail boat spring a leak. The regressive content of the last part of this metaphor does not require that I say anything about anxiety in the creation of settings.

2. In our society, at least, creating a setting involves one with a variety of existing settings which may have different purposes and traditions but with which one must develop and maintain relationships. One comes quickly to recognize that (as in the case of a modern nation) the problems of coordinating them in a non self-defeating way are enormous.

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[2] This probably is not always the case, particularly when those with responsibility approach the task in a predetermined, businesslike way, armed with organizational charts which prevent the anticipation and recognition of substantive problems. The generalizations offered above hold, in our experience, for those individuals with acute awareness that the relationships between an organizational chart and the actual functioning of a setting may be like that between an individual's curriculum vita and the "real individual."

3. At every step of the process, and particularly in the earliest stages when relatively few people are involved, every decision, or action, tends to have immediate consequences for the group. My point does not concern goodness or badness of action or decision. What I wish to emphasize is that decisions and actions have consequences for relationships within the small group; and, since in the earliest stages the small group tends to consist of those in important positions, unawareness of this fact, or not having built-in vehicles for insuring awareness of it, can engender a pattern or style of talking and relating which, over time, results in full-blown organizational craziness. (The only good argument I can come up with against the use of the term "craziness" is that what we call craziness seems to be the norm for organizations.)

4. In the earliest stages, as we indicated, there is usually a small group of individuals involved--this is practically always the case when a physical structure has to be built to house the setting. The point at which this small group begins to enlarge--and this enlargement may involve one or more newcomers--is always a danger point because it involves the "old" and the "new," the insider and outsider, those who have belonged and those who want to belong, those who have had power in some form or other, and those who will want power. When this enlargement takes place very rapidly, and *again when there are no built-in vehicles for anticipating, recognizing, and handling the problem*, the setting tends quickly to become a highly differentiated one in which the parts are maladaptively related *and the overall purposes of the setting become secondary to the purposes of its component parts*.

5. Creating a setting is, from a purely intellectual point of view, a fantastically complicated array of problems. In fact, its conceptual complexity is of such a high order that when its complexity is recognized by those whose responsibility it is to create a setting, it results in strengthening the tendency to simplify the problem. The need to simplify problems as a defensive tactic to protect the self is inversely related to the degree of awareness of the complexity of the issues and its consequences. This is identical in principle to the situation of the artist who knows what he wants to create but is faced with the knowledge that he cannot, or will not, be able to do it. In both instances the consequences can be disastrous for the individual and his products.

6. There is an ego-syntonic expectation that there will be a time in the history of the setting when there will be few problems (within the setting and between settings), so that those who create the setting can look forward to reduction in the level of intellectual and emotional turmoil required by the need for vigilance and the anticipation, recognition, and handling of problems. It is identical to the myth entertained by most people entering therapy or analysis, i.e., when it is all over they will be conflict and anxiety free,

competent to handle any or all problems. In the case of the creators of settings, the awareness that the myth is a myth can wittingly or unwittingly set into motion a way of viewing and relating to the setting, so that the level of struggle is indeed reduced at the same time that the level of craziness in the setting increases--one produces what one wanted to avoid.

Some Further Aspects of the Beginning Context With Special Reference to Mental Retardation

In order to elaborate somewhat more concretely on the significance of the beginning context, let us take the following situation:

> Let us assume that legislation has been passed to enable an appropriate state agency to build a new facility for the mentally retarded which will develop a variety of programs, day care and residential, for a circumscribed geographical area. A director for the new facility has been appointed.

My interest is in how this director thinks and plans from the time he assumes his responsibilities. I need not labor the point that my interest reflects two considerations. The first is that the problem requires that we know the director's thinking and planning processes--those are our "data" without which we continue to operate in the realm of opinion as to the beginning context of setting creation. It may surprise you to learn that I have not yet found a single description of the beginning context that anybody would dignify with the adjective "adequate"--and I have searched the literature in many fields. The second consideration in my interest is the assumption that the beginning context is fateful for what comes later, i.e., the seeds for later success or failure are contained in the beginning context. That this is a safe assumption should increase one's puzzlement as to why it has not been systematically studied or tested--after all, the history of science could be written from the point of view of how dangerous "safe" assumptions are.

I have no data to present about the thinking and planning processes of the director in the beginning context. However, in the past decade I have had the opportunity to interview many directors, albeit after the stage of the beginning context. What I can report to you is what they did not think about or plan for but which they later felt caused them no end of grief. I can only list and briefly discuss some of the factors which were little or not at all in the director's thinking.

1. From a developmental viewpoint, the appointment of the director comes relatively late in the beginning context. That is to say, before the director's appointment, a relatively large number of individuals and groups--varying markedly in status, influence, and point of view--have in one way or another attempted to influence what the setting ultimately should be. In each instance the director "knew" there was a

prehistory, but this knowledge never resulted in a searching attempt to determine the prehistory, to assess its implications and complications for the future, and to take steps to deal with them. After reviewing their past experience (i.e., their acts of omission) in their present positions, all the directors agreed with the statement by one of them: "Before you start shaping the future you had better know and deal with the past."[3]

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[3] The most sophisticated attempt we know, in deed and word, to create a new setting is that of Dr. Ira Goldenberg of the Yale Psycho-Educational Clinic. For 6 months he was director of a Residential Youth Center for hard core, inner city youth between the ages of 16 and 21. Prior to the center's opening he selected and trained a staff of nonprofessionals who would carry on after his 6 months as director. One and a half years after he left, the center continues as an exciting, helping setting every bit as effective as similar settings run by professionals. Dr. Goldenberg's book will, I predict, be a major contribution to the long-neglected problem of how to create and maintain health settings. In connection with his experiences in opening the center the following is relevant:

> "There is a myth, publicly disavowed but privately protected, that an institution is born on the day it opens its doors and starts doing 'business as usual'. We refer to this as a myth only because, public protestations to the contrary, institution-builders often act as if what they do, the decisions they make, and the actions they take before a new program becomes operational bears little relationship to, and has few consequences for, the eventual appearance, acceptance, and success of the program itself. But if there was anything to be learned from our prior involvement in the community it was this: that the fate of any new program--whether or not it survives; and even if it survives, whether or not it achieves or approaches its goals--is dependent not only on the soundness of its ideas but also on how and in what manner it is introduced into the community. In short, there is an intimate relationship between the problems of conceptualization, planning, and implementation on the one hand, and how a program looks once it assumes an existence of its own on the other. The two are inextricably bound to each other, and what may well signal the beginning of that self-defeating process through which new and often innovative programs create the conditions for their own destruction, is the belief, the myth, that this is not really so."

2. It will be recalled that in the circumstances I described it was stated that legislation was passed to enable "an appropriate state agency" to build a new facility. The word "appropriate" was, of course, not fortuitous and was meant to emphasize that there was already an existing, differentiated, ongoing structure, each part of which could be counted on as having two related concerns: first, that the new facility would "fit in" with what was already ongoing (although "fit in" would be defined differently by the different parts of the structure); second, that the new facility should not intrude into the existing domains. It has to be said that most of the directors were in varying degrees aware that by their appointment they had become part of a social system or structure which could affect them and their plans, particularly if, as is often the case, the director was previously a part of this structure in another capacity. But again, in no instance did a director explicitly and planfully act on this knowledge so as to minimize the problems and conflicts which later confronted him by virtue of the fact that he was part of a particular system--and the severity of the problems and conflicts are proportional to the degree to which the director views himself, or is viewed by others, as an innovator. The point deserving emphasis is that what I am describing takes place independent of the personality of the director, i.e., it is perhaps a defining characteristic of a social system or structure that the introduction of a new component affects and in turn is affected by the existing structure. Personality is an added variable which almost always is seized upon in a way so as to obscure the characteristic workings of the system qua system. Conflict within the system is usually experienced and explained in "interpersonal" or personality terms at the expense of the recognition that such conflict reflects the nature of the system--a lack of recognition that tends to guarantee that innovation will result in surface change, and that the more things change the more they remain the same.

3. Unlike the first two considerations, the present one does concern what directors or superintendents do. It focuses on an understandable and unwitting process which illuminates the first two points at the same time that it has a dynamic of its own, precisely because it reflects an "individual" way of thinking. I am referring here to the director's tendency to view the program and the planned facility as his, i.e., these things are his, psychologically he owns them, and his world is simplified into "inside and outside," "friends and strangers," and "we and they." It is an unwitting but profound process defining boundaries which prevent recognizing the significance of prehistory and the dynamics of the system of which it is a part. Let me be quick to add that this process is in the nature of a double-edged sword. On the one hand, under certain conditions and at certain times the erection of boundaries and walls can protect and foster productive growth and innovation. On the other hand, screening out the "outside"--acting on the basis of the myth that it is not part of an existing structure or that it is not embedded in a community--can set the stage for later catastrophe. At the very least it maximizes the number and extent of

future problems. Etiologically speaking, the problems in large part stem from our failure (by no means limited to directors) to think and conceptualize in terms of structure and system. This failure automatically reduces the amount of information which can become available as well as awareness of the number of different alternatives for action, and prevents one from recognizing that the consequences of actions one has taken has to be viewed not only in light of what one did but also in light of what one might have done. What is crucial to recognize in the beginning context is that each decision or planning step can be conceived as involving a universe of alternatives and that one's major task is to avoid constricting this universe. To the extent that the director's universe of alternatives for action is defined primarily by a psychology of the individual to the exclusion of considerations of structure and system, he is dealing with a restricted universe in which virtues tend to be made of necessities, i.e., things are done because they have to be done and there are no alternatives.

The Universe of Alternatives in Residential Care

It is appropriate at this point to ask a deceptively simple question: how do we understand why, in this country, at least, the pattern of residential care has been so consistent, i.e., a relatively large number of children are housed in a place staffed by a wide variety of professional and nonprofessional personnel? This is even true in a state like Connecticut where they have decentralized the state into regions in each of which there is a regional center (see Klaber's chapter). In each regional center there are residential facilities, and although the number of residents is far fewer than in the usual monstrous institutions, it is still true that the residents are in that regional center. It seems, unfortunately, to be the case that a large part of the answer to the question involves the failure explicitly and systematically to list and evaluate the universe of alternatives in regard to residential care.

There is more involved here than the weight of tradition, although that is an important factor. What I have been impressed by is that even in instances where the conditions for innovation were ripe those who were responsible for creating the settings did not examine the alternative ways one could view and implement residential care. It is ironic that in planning buildings these same people can spend vast amounts of time creatively examining the alternatives for design and allocation of space, but fail to act and think similarly in regards to the alternatives to housing the children in one locale. Let me illustrate my point by relating the following experiences: On four occasions I had the opportunity to ask the following question of a group of individuals who either had or would have responsibility for creating an institution for mentally retarded children: "What if you were given the responsibility to develop residential facilities with the restrictions that they could not be on 'institutional land,' no one of them could house more than 12 individuals, and no new buildings could be erected?" The following, in chronological order, were the major reactions of the different groups.

1. Initially the groups responded with consternation, puzzlement, and curiosity. For some members of each of the groups, the question seemed to produce a blank mind, but for others it seemed as if the question quickly brought to the surface all their dissatisfactions with the usual mode of residential care and stimulated consideration of alternatives.

2. In the early stages of discussion, the chief stumbling block was the restriction that "no new buildings could be erected." I should say that throughout the discussions I adopted a relatively nondirective approach and tried only to answer directly questions which would clarify the meaning of the initial question. For example, when asked if one could remodel existing structures, I indicated that this was, of course, permissible. When I was asked if there was any restriction as to where these houses or small buildings could be bought and rented, I said there were no such restrictions. The point deserving emphasis is that many individuals struggled for some time until they realized that there was no one way to act and think but rather that there was a potentially large universe of alternatives for action from which they could choose In addition, as some individuals came to see, there was no necessity to choose only one alternative, i.e., one could and should proceed in different ways at the same time.

3. Midway in the meeting the behavior of the members began to change in rather dramatic ways. Whereas before most were hesitant, deliberate, and cautious in their remarks, they now seemed to respond as if they were engaged in an exciting, intellectual game in which one possibility led to thinking about other possibilities, and what at first seemed to be unrelated were then seen as crucially related. Faced with the task of creating settings they truly began to think and talk creatively.

4. In two of the groups--and for reasons I cannot wholly account for--a plan for residential care evolved which brought together the renovation of substandard housing, training programs for nonprofessional personnel, volunteer services, and neighborhood involvement and responsibility. In short, these two groups were no longer dealing with mental retardation in its narrow aspects but in the context of some of the most crucial aspects of what has been termed the urban crisis.

One of the more experienced superintendents pointed out to his group that in the plan they had discussed "we are meeting more social problems, and providing more meaningful service to children and their families, at far less money than we are now spending." It was indeed remarkable how intellectually fertile the discussions in these two groups were. For example, one of the group members made the point that if these small housing units were strategically placed around our high schools they could be used by the schools in at least three ways: for educating these youngsters about mental retardation, for purposes of training child-care workers, and for enlisting volunteers for recreational and other purposes. Another group member, in the context of a discussion about food preparation in these small units, maintained that if neighborhood participation and responsibility were taken seriously, food preparation and feeding could be handled on a volunteer basis, besides which the food would probably taste better. In my opinion, the creative thinking and planning that went on in these two groups were, in part, a consequence of a process which permitted the members to think not only in terms of the retarded child but in the context of pressing urban problems which ordinarily are not viewed in relation to the field of mental retardation.[4]

It is, of course, significant that the members could come up with approaches to residential care which they had not considered before and which deserve the most serious consideration. But what I consider of greater general significance is the fact that in the usual ways in which such settings are created the universe of alternatives is never described or thought through. It is my opinion that research on how settings are created will ultimately have a more beneficial impact on the quality and varieties of residential care than any other single thing we might do. Up to now we have focussed research on the recipients of residential care. I am suggesting that we will learn a great deal about the recipients by turning our attention to the values, assumptions, and thought processes of those who plan for the recipients.

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[4] Mention should be made here of a development which is taking place in Connecticut and which may have profound effects not only on programming in that state but in others as well. I refer here to the new Central Connecticut Regional Center, where a serious attempt is being made to view and implement a pattern of residential care very similar to that evolved in the two groups described above. This attempt is being carried out primarily by two people: Mr. George Zitnay, director of the new center, and Dr. Frances Kaplan of the Yale Psycho-Educational Clinic. Needless to say, this pioneer effort would not be possible without the support of Mr. Bert Schmickel, Deputy Commissioner of Mental Retardation. This new center legally came into existence July 1, 1967. It had and has no buildings and practically no staff. At this time, 1 year later, literally scores of individuals and agencies are involved on a working level not only in the development of services but, more important, in the actual rendering of service--and in almost all instances the individuals and agencies heretofore had no service relationship to the problems of mental retardation. In my experience what has been accomplished there in 1 year is the best example of what should be meant by a program being psychologically and socially in and of a community.

Future Directions

So far, I have not gone beyond the appointment of the director--we have barely discussed programs, buildings, staffing, children, parents, communities, etc. In short, we have not gotten to the growth of a complicated social system. What I eventually hope to do is to demonstrate two things. First, that the beginning context--by which I mean its prehistory, the thinking and planning processes of its director, and the structure of system from which the setting has come and to which it will be related--is crucial to the development and understanding of what comes later. Second, that the limitations and dangers inherent in the beginning context (as I have too briefly described them) are manifested with great clarity as the setting becomes differentiated. That is to say, there develops within the setting a variety of subdivisions each of which has its director who thinks in terms of his subdivision in the ways characteristic of the overall director. The result is what I have termed organizational craziness, in the context of which the goals of service are drastically and adversely affected.

The conditions described by Blatt and Kaplan, those described by many in regards to our urban schools, those that exist in many of our state mental hospitals--in these and other settings, self-defeating characteristics can in large measure be traced back to characteristics of the beginning context. That is certainly not the whole story, but it is an important part of it and one which has not received attention. However, we cannot see the problem until we first recognize that the creation of a setting (or the repair of a sick one) is not a clinical problem, or one which is contained in or derivable from theories of individuals or individual personality, or a communication problem which is solvable by legislating talk, or an administrative problem requiring refinement of organizational charts, or a problem requiring motivation, good will, and abundant energy. The problem requires a way of thinking and conceiving which recognize the existence, characteristics, and dynamics of social systems and structures; the consequences of these for stating and choosing alternatives for planning and action; and the development of means and vehicles from the beginning, so that (to change Gardner's words) eyes will see, ears will hear, and minds will face the evidence before them.

My generalizations (highly selective) may or may not be well stated, and it may be that we or others will find out over time that, as is usually the case, understanding the interrelationships among issues and processes is less likely to result in conceptual distortion than becoming enamored of one or another aspect of the complexity. The two purposes for these generalizations were to suggest the degree of complexity with which we are dealing, and to suggest that the craziness of settings may have their roots in the earliest stages of their development.

The creation of settings is not a problem contained in or derivable from existing psychological or social science theory. I am of the belief that it may well be the problem which will facilitate the development of that kind of heightened consciousness or awareness which will lead to conceptions that will both encompass and transform existing theories of man and society. The transformation will result in conceptions of man in society. If such a transformation begins to take place--which is but another way of saying that our styles and categories of thinking will have begun to change--one may look forward to the day when those in our fields of inquiry and practice will look with understanding, condescension, and amusement at our current tendencies to win battles and lose wars, to react instead of act, to engage primarily in works of repair instead of works of creation, and, worst of all, that the crucial problem we failed to see, and hence to control for, was how our theories and practices were the inevitable consequences of our times, society, and history. Freud taught us a good deal about why we had to take distance both from ourselves and the patient. The next difficult task is to reach that higher elevation which may enable us to catch insightful glimpses of the interrelationships among ourselves, our theories, practices, and society. But to strive for the higher elevation implies (as it does in the act of seeking personnel therapy) that we have made the crucial decision that movement and change are necessary.

To some people the contents of this paper may be seen as vague or irrelevant, or too abstract, or worse yet, unimportant and boring--reactions which stand a fair chance of being valid if only on the basis of an actuarial assessment of papers in general. But there is one opinion or observation which I would request such people to consider as one possible source of their reactions. Such reactions tend to come from people who prefer to think that what they are and what they do, what they have been and what they will be, is not an important measure explainable by the characteristics and dynamics of the social structures and systems in which all people in our society have been, are, and will be. To think otherwise, for some people, is to admit the possibility that it is theoretically indefensible to maintain that as individuals we are masters of our fate and captains of our soul. Is it not noteworthy that in order to maintain a psychology of the individual and individualism we resort to the words "masters and captains," which so clearly denote particular systems or structures? Our thinking and our actions inevitably reflect the setting we are in and the settings in which we have been. As I said earlier, settings are not the whole story but they are that part of it to which we have given little or no systematic attention.

Very recently, Cleland and Cochran (1968) published a brief paper entitled "Demographic Characteristics of Superintendents in State and Private Institutions." At the beginning of their paper the authors state:

> "In the field of mental retardation a renaissance has occurred during the past decade and one encouraging sign is an increased research and training interest in institutional personnel-mainly attendants. A similar interest in leadership personnel has yet to evolve and the present study reflects

> an effort to describe certain characteristics of administrators occupying the top position in state and private facilities for the retarded. If more is known of leader characteristics it may be possible to understand more fully the barriers and gateways to institutional change."

At the conclusion of the paper these authors state that their study provides "a beginning effort to complement existing knowledge of other institutional employees. Cooperation between various employee groups, professional and nonprofessional alike, should theoretically advance if information is provided on all groups and more intensive study of this numerically small but target group of leaders might lead to improved institutional operations."

I heartily agree about the significance of these kinds of studies. However, if only to be consistent with my own position, I would have to maintain that the basic problem is not one of studying different groups within a setting but how to conceptualize the setting itself in its developmental aspects so that we better understand how and why differentiation takes place, the implicit and explicit factors which make for barriers to change, and, most important, forces us to face the question of the alternative ways in which structure and function can be related. At the present time the question of the relation between structure and function is answered primarily on the basis of tradition rather than on the basis of theory and research. But, as John Dewey pointed out in a beautiful paper, "Science and the Future Society," we have not yet learned to use "organized intelligence" to bear on the problems of living and working together.

It is precisely because of the rate of setting creation in the field of mental subnormality that there is the opportunity for this field to make a contribution to the theory and practice of setting creation which would have significance far beyond its borders. If this problem is not recognized and studied, we will continue to confuse action with progress, programs with accomplishment, the expenditure of money with improvement, and the failure of a setting with bad luck or the obtuseness and evil of individuals. The modest research program which I and some colleagues have been engaged in lends unequivocal support to the idea that settings misfire in the same way that so much research misfires: the conceptualizations which generate the creation of settings (or research) are either oversimplified, fuzzy, or simply wrong.

It is likely, as the present book suggests, that in this country we are at the beginning of a new era in patterns of residential care. For example, the suggestion has been made that the federal government make it financially possible for parents to have freedom of choice as to where their retarded child will be placed, a suggestion which would give use to many small and private residential facilities. This proposal is viewed as one way of beginning to eliminate or reduce the number of our large state institutions some of which have the scandalous characteristics depicted by Blatt and Kaplan. As a reaction to our present way of handling residential care, the proposal has merit. However, I must express the serious reservation that the proposal perpetuates the tendency to think primarily in terms of the retarded child and not in terms of the possible relationships between the field of mental retardation and other community needs and problems. To the extent that a plan for residential care does not reflect the systematic exploration of the alternative ways in which it can be related to other community needs and problems--that is to say, truly integrated with the activities of diverse groups and settings in the community--to that extent the field of mental retardation and the larger social community will be robbed of the benefits they can derive from each other.

In their recent book Sarason and Doris (1969) have discussed in some detail the history of the relationship between the field of mental retardation and the larger society. They describe how in various ways changes in the larger society affected the understanding and management of mentally retarded individuals--and those effects were usually not beneficial. As we enter a period in which new patterns of residential care are being seriously discussed we have the possibility, perhaps for the first time, of planning in ways which would make it possible for the field of mental retardation beneficially to affect the values, consciousness, and activities of the larger community. But this will be possible only to the extent that we concretize the difference between being physically in a community and being psychologically and socially a part of it.

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Part VII: Toward New Service Concepts

Chapter 15

The Free Choice Principle In the Care of the Mentally Retarded

Robert E. Cooke
The Johns Hopkins University School of Medicine

THE FREE CHOICE PRINCIPLE IN THE CARE OF THE MENTALLY RETARDED

This presentation is the product of the collective thinking of several members and staff of the Research and Advancement Subcommittee of the President's Committee on Mental Retardation. Patrick Doyle, Matilde Krim, Allan Menefee, George Tarjan, and Donald Stedman (1967) were of particular help in developing this concept. However, I take responsibility for its consequences.

The Medicare Act of 1965 initiated a revolution in medical care for the elderly, and for the indigent and medically indigent. Title V initiated comprehensive care of children; Title XVIII initiated a health insurance program, paid for during younger working years, and utilized after age 65; Title XIX initiated a free choice system of medical care for the poor rather than the previous welfare system which forced many to city and county hospitals for the poor.

I am proposing that we need a Mental Retardation Care Act of 1969, equivalent to the Medicare Act of 1965, making possible the individual selection of programs and facilities by each family of the retarded, so that not only public (state or local) institutions will be providers of care.

The Medicare Act of 1965 provides for reimbursement, on a full cost basis, for expenses in private or public, profit or nonprofit hospitals; in nursing homes, proprietary or nonprofit; and for private physician's services.

What impact has this act had on the users and the purveyors of service? What has been the response of the public and the private health industries to that act?

In less than 2 years of operation, there has been a dramatic shift from city clinics and city hospitals to private physicians and private hospitals even though these latter may be less accessible. Indeed, there has been a rejection of public type care: for the first time, city clinics and city hospitals are experiencing decreases in registration and patient census. Even Cook County Hospital is no longer overflowing. Free choice has moved the consumer away from public medicine. I am told that a neighborhood health project of the Office of Economic Opportunity was rejected by the poor of San Francisco. They are tired of long lines, massive facilities, and impersonal care, and they want a middle-class system of care.

In response to this demand for private services, facilities are being built or altered to provide more acceptable environments for patient care. City hospitals are undergoing face-lifting operations that are transforming the long benches to privatelike clinics.

More pertinent to our argument in mental retardation is this remarkable statistic from the Social Security Administration: in only twenty-one months of operation of the Medicare Act, the number of nursing homes has increased from 1,200 to over 4,000; and while many of these are proprietary, almost all meet accepted standards. Likewise, the Small Business Administration reports that the most common low interest loan which they currently advance is for nursing home construction.

The simultaneous presence of funds to support private care as well as demand by patients for such care has created a burgeoning new industry. In a free enterprise system such as ours, the presence of consumer demand and consumer capability to pay rapidly leads to better facilities and better programs on a competitive basis.

Yet neither new facilities nor new program plans could be operated without professional manpower. What has been the response here? In fact, an enormous number of trained nursing and medical personnel has appeared--almost "out of the woodwork"--because these new facilities are small, very personal, easily accessible in our suburbs or near our population bases, close to the homes of nurses formerly in retirement, close to physicians, to volunteers, close to the homes of families of the beneficiaries.

Let us now contrast extended care for the aged under Title XVIII of the Medicare Act, or acute care for the poor under Title XIX, with the care of the severely and profoundly retarded in most of our states.

Unless parents are indigent or medically indigent (e.g., an income under $3,100 for a family of four in Maryland), or unless they carry an unusual variety of health insurance, they must bear the full cost of diagnostic and therapeutic studies in the first several months of life of a severely handicapped child. Birth defects are omitted from coverage in many health insurance plans. It is little wonder that young families are wrenched apart with hospital bills that disrupt the future of the normal as well as the affected child.

As the handicapped child grows, opportunity for day care is limited by the tenuous financial situation of private or, sometimes, public agencies. Rarely are young couples able to meet the full cost of even day care. What if care out of the home is needed for the well-being of the child or family? What are the options for the family? For all practical purposes there are no choices. There is only one answer: public care.

Extended care in private facilities for the mentally retarded is almost never covered by private insurance, not even by major medical benefits. The cost of private residential care is geared more to the less severely handicapped, especially those with emotional disturbance, and amounts to four to eight thousand dollars per year. Such costs cannot be met by other than a small segment of our upper class. Not only the lower class, but even the middle class in a sense becomes medically indigent and must turn to public care for the retarded.

Where is this public care located? Usually many miles away, sometimes even across state lines. And what are these public facilities like? Large, old--planned years before our modern concepts of handling the retarded were developed--impersonal, crowded.

Yet these facilities represent a major capital investment for the state: large physical plants, large civil service payrolls, and large commitments which minimize change simply from the enormous inertia of such monolithic systems. Even now, many of these excessively large facilities are being enlarged still further.

With all respect to the efforts of programs aimed at improving existing residential facilities, these are stopgap measures. Only a totally new approach can produce major changes.

What if public institutions do not satisfy parents? What if care is poor? What if distances are too great? What if legislatures limit appropriations?

Now, under our present system, families have no options--no more free choice than the medically indigent 3 years ago--only the "city hospital" for the retarded; some are good, many are bad.

How then can options be developed? How can the free choice principle be applied to long-term as well as acute care? By providing a new basis for reimbursement: insurance, supported on the widest possible base, and designed to meet unexpected and catastrophic financial burdens.

The application of the same principles as those of the Medicare Act to the care of the severely and profoundly handicapped child would make possible, on an insurance basis, payments to families to assist in providing care where families rather than public officials prefer it. Families could then choose facilities and programs, day or residential, which were most acceptable to them, just as with acute medical care.

With consumer demand and consumer capability to pay, a multiplicity and variety of facilities to meet a variety of needs would be created, just as with the Medicare Act. Small size would be inevitable because of limits on local capitalization for such ventures. Small size, intimacy, personal involvement, volunteer and parent participation would result. With demand, new job ladders, new job opportunities would arise close to home, accessible as well as available to the married women and the volunteers, young and old, of urban and suburban society.

Nonprofit and proprietary both could flourish--regulated more by consumer satisfaction and competition, by parent boards and community leaders than by legislative committees or even boards of trustees that "visit" the institution once a year.

How would an infant, child, or adult enter this new system? By application from the family, or an agency acting for the family. Determination of disability would be made by medical, psychological, and other disciplines. Indeed, appropriate study for each child would be guaranteed as a byproduct of this system.

The comprehensiveness and cost of such a program would be dictated by demand. Medical care, medically oriented therapies, nursing, physical therapy, behavior analysis, and the like would be provided under such a Medicare extension. Since education is essential for many of the severely handicapped, the cost of education activities should be borne by state or local educational structures in those cases where such is not provided by the public schools. This principle should be maintained because education is a public responsibility by tradition so firmly rooted that it could not and should not be shaken. Within limits of their income, families would be expected to bear costs to the same extent they would bear costs for a normal child at home. Thus, these three components would combine to meet the total costs of services.

The reasonable cost of such a program nationally would approximate 1.2 billion dollars annually, liberally calculated. Much of this would be a replacement for present expenditures from state and local appropriations. To an employed person it would represent an increment of 0.19 percent of taxable base income, and a similar increment to the employer--a price to pay, not insignificant, not easily bought by politicians, but one that labor unions and middle class will buy.

Indeed, the possibility exists that the cost may be no greater than in the present system despite markedly improved services because of the reduction in overhead that inevitably accompanies massive facilities, massive personnel rosters, with their supervisors and supervisors of supervisors.

To this point I have presented only the positive aspects. Needless to say, there are potential flaws: parents and government exploited by entrepreneurs; government exploited by parents and physicians; parents might not follow adequate counsel; parents may die, leaving the child without guardian. This last problem must be faced realistically, and a surrogate parent, a life manager behind the scenes, must be created instead of the dependence upon the security of isolation in the large institution where the superintendent is the life manager for thousands.

Yes, this is an extension of social security to a different group, but not to a different purpose.

Some may say it is a step down the road to more socialized medicine. To those I would say the present system is the ultimate in socialized medicine: state facilities, state-operated, state-controlled, state-regulated.

There are concerns: there are dangers. California is partly experimenting, but inadequately so, without an adequately broad base of insurance coverage. Canada seems to be moving successfully in this direction.

Sooner or later, parents of the retarded will demand options--options which they control, not others.

In a free society, sooner or later, free choice is inevitable, even for our least privileged: the retarded. The wise society will act speedily to create a mechanism for this free choice, and bring to parents of the retarded everywhere a new cause, a new involvement, a new opportunity.

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Part VII: Toward New Service Concepts

Chapter 16

A New Approach to Decision-Making in Human Management Services

Wolf Wolfensberger
University of Nebraska College of Medicine

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A NEW APPROACH TO DECISION-MAKING IN HUMAN MANAGEMENT SERVICES[1]

The Problem

For the purposes of this essay, I will use the term "human management" and "human management services" to refer to entry by an individual or agency, acting in a sanctioned capacity, into the life of another person or persons, purportedly in order to benefit either such person(s) or a larger social system surrounding him, such as his family, his community, or society more generally.

Public agencies providing human management services, and to some extent nonpublic agencies rendering such services at public expense, are commonly viewed as representatives, even interpreters, of the social norms and intents of the larger society, particularly as these are expressed by law. Thus, when a person or family approaches an agency, or is referred to it, the agency implicitly or explicitly plays the role of the mediator between society and the prospective client.

Generally, services are provided via a stylized pattern of agency-client interaction. Usually, this interaction involves a specific agency with a specific client or client family. After referral and/or application, the agency processes the client through usually well-developed and relatively routine procedures that are designed to identify whether the client needs any services offered by the agency; whether he meets criteria for eligibility for such services; which services, if any, should be offered or provided; what conditions should surround such services; and whether the client should be referred to other agencies for additional or alternative services. If a client is unhappy with one agency, he generally can go to another, and the entire process of assessment and decision-making might be repeated there.

Many societal services, once considered utopian, are now viewed as rightful. Universal and public education, pension schemes, and certain types of medical care are examples. If several alternative service options exist for a given client, and if all these alternatives can be considered rightful, it is widely accepted that the client has the right to choose which option or even combination of options should be implemented. In its extreme form, this view is exemplied in regard to the residential placement of a presumably retarded child; here, a widely accepted assumption has been that parents have the right to judge whether or not they want to, or are capable of, raising such a child at home.[2] Parents are seen as having the right of divesting themselves of such a child not only physically but also emotionally and legally. Thus, court commitments relieving parents or guardianship as well as of custody of the child have been common, accepted, and in many cases even defined as desirable. Once a child was legally committed, the parents were under no obligation to maintain any contact with the child. If they moved out of their state, they apparently could not even be compelled legally to contribute to the child's support, i.e., to pay the fees the state or county usually charges parents for at least partial support of institutionalized children.

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[1] The writing of this paper was supported by USPHS Grant HD 00370 from the National Institute of Child Health and Human Development.

[2] It should be noted that in our society, a parent generally is not considered entitled to divest himself of a young child unless the parent is an unmarried mother, or unless the child is believed to be retarded (e.g., Dybwad, 1961, 1962).

The assumption that parents have the rights indicated above are expressed not only in current laws but also in innumerable stereotyped statements in the literature to the effect that "the decision to place is the parents' and not the agency's."

I propose that it is time to reconceptualize certain social policies underlying many human management services. Specifically, I am suggesting that most human management agencies, as we now know them, are not, or at least not any longer, in a position to function effectively as mediators between society and citizens. There are at least three reasons. Firstly, our culture is becoming increasingly complex, and agencies find it impossible or unjustifiably expensive to cope with the complexity of laws, regulations, resources, record and data management, etc. secondly, agencies often fall into the error of, in effect, making social policy decisions that should be made at a higher level of social organization. The setting of certain service priorities and sometimes the failure to set such priorities can both fall into this category. Thirdly, agencies often abdicate responsibility to communicate needs for certain social policy decisions to higher levels of social organization, instead continuing to render human services in a stereotyped fashion long after the original operating rationales are no longer adequate.

In addition to the need of fitting service operation to social policy, there is another problem. Agencies are increasing in number while continuing to function in essentially uncoordinated fashion. The service needs of a client may be broad and continuous, while service provisions may be narrow and fragmented. Specific agencies usually have only a narrow range of services to offer, and therefore they frequently render the service they can offer rather than the one that is needed. They may even offer a long-term and difficult-to-reverse option (e.g., institutionalization) available at a given moment in order to meet a need that is likely to be of short-term duration (e.g., parental illness). Thus, even if rationales were strong, even if social policies were clearly defined and understood, and even if services were amply financed, the client might still not receive adequate or optimal services because of the fragmented nature of our current service structure.

Besides proposing that the agency structure of the past is no longer adequate as an interpreter of societal intent in regard to human management, I also suggest that it is not capable of rendering human services based on a social policy consistent with cost-benefit considerations. Yet such a rationale, I propose, is nothing less than essential if we are to cope effectively with the demand for human management services in the furture.

The Cost-Benefit Rationale

Briefly, a cost-benefit rationale implies that when a problem is to be attacked, those approaches should be employed which, within the limits of certain criteria, are likely to attain the goal at least cost; or which result in the most favorable cost-benefit ratio. Cost can be defined in many terms, e.g., time, space, money, manpower, effort, lives, and others.

Within a cost-benefit scheme, the distinction between effectiveness and efficiency must be made. An effective approach is one that reaches a goal; however, not all effective approaches are efficient: an efficient approach attains a goal at low cost.

The question may be raised whether human services really should be based on cost-benefit considerations, and there is much sentiment that they should not, Indeed, personnel in our current human management agency structure, having been trained in a clinical tradition, often react emotionally and reflexively against anything resembling a cost-benefit approach. However, two overwhelming realities are emerging that are bringing more and more people to accept cost-benefit rationales.

One such reality is the shortage of human service manpower *vis-a-vis* the rising and acknowledged need for such services. Professional manpower projections in many large human service areas do not foresee an adequate manpower supply for the service demands of the immediate or intermediate future. In fact, in some areas, a widening gap is predicted. Thus, one cannot escape the question as to who is to be served when not all can be served, and how to distribute what limited service there is and will be.

The second reality alluded to is the growing realization that not even the richest country in the world has unlimited natural and financial resources. One can already hear questions raised whether millions of dollars spent in one area of human service would not have accomplished what billions spent in other areas failed to do. Also, the public is beginning to be told that it will cost billions in the near future merely to keep our water drinkable and the air breathable, i.e., to maintain our most basic life support systems. An example a bit closer to our topic was given by Dybwad (1962), who pointed out that the cost of inappropriate institutionalization of mongoloid infants could finance extensive maternal and child health services crucial in the prevention of large numbers of cases of retardation.

While decision-making dilemmas of human management have been with us so long that they should have been faced well before now, they have been sharpened by recent events, such as organ transplants and renal (kidney) dialysis (e.g., Haviland, 1966; Murray, Tu, Albers, Burnell & Scribner, 1962). Let us assume that a heart surgery team could perform one heart transplant for every 50 eligible applicants at any time. Who, then, is to select the surgery client, and by what criteria? And is this not a decision reaching so far into social and ethical areas as to require a social rather than merely medical judgement, and a legally defined rather than merely informally established decision-making mechanism? One step in that direction has been taken in some settings in regard to the allocation of renal dialysis resources, where such allocation decisions are made by groups which include community leaders such as lawyers and clergymen in addition to physicians.

While sentimentality and perhaps ill-rationalized 19th century humanism might have it otherwise, cold reality will increasingly demand that human management decisions of the future, like other national practices, be based upon a cost-benefit policy if our society, perhaps even mankind, is to survive.

A New Policy and a New Mechanism

The New Policy

I am proposing that as a matter of social policy, cost-benefit considerations should be made the basis of human management services; concomitantly, I am suggesting that in order to carry out such a social policy, we will need a new human management mechanism.

In order to develop the new policy, certain rights and duties involved in the interaction between citizen-client and societal services as rendered by publicly supported human management agencies must be clarified. Specifically, I suggest that in regard to publicly funded human services, society should take a more direct role in setting eligibility rules, and in defining what service options it will offer to a client. Clients would retain rights to refuse those options offered by society, but would not be perceived as having the right to utilize all options that society has at its disposal and that may meet the client's service needs. In other words, the new policy would not only establish eligibility; it would offer options on the basis of cost-effectiveness criteria, where cost and effectiveness would be judged in terms of social, moral, emotional, financial, and other interests of child, family, community, and society.

An example from the mental retardation field will illustrate the principle. A problem-ridden family with a severely retarded child may come to a societal representative (e.g., an agency) for service. The only options that are relevant and that exist at that point in time and space may be institutionalization, visiting homemaker services, day-care services, and income subsidy. Let us assume that a cost-benefit policy were in operation, and that the parents requested institutionalization of the child. The societal representative might then establish that the family, being under extraordinary stress, is eligible for services, but that services other than institutionalization can provide adequate relief and will be more consistent with the interests and service needs of all involved. Thus, visiting homemaker services and day-care services are offered. At this point, the parents could elect to reject these two offers, but in that case they would be denied the right to place their child into an institution at public expense, while retaining the privilege of pursuing services at their own expense.

In the past, the family in the foregoing case typically would have been handled one option at a time. It could conceivably apply to one or more of a number of uncoordinated agencies offering only one or a few options each, and be processed without true regard to the option optimal to anyone; the option maximizing the benefits of child, family, and society simultaneously; or the option that would accomplish the latter at least "cost." Instead, the family had to be merely "eligible" to be served or placed on the waiting list for service, and in the latter case, they might have been served when their turn came up, regardless of the constellation of circumstances that differentiate one case from another.

In order to implement the new policy, there must be extensive revision in the basic mechanisms by which human service decisions currently are made, and by which such services are rendered. Most essentially, agencies must surrender decision-making functions as to both client eligibility and option offering to a higher level body, thus permitting societal intent to be expressed more directly in the service process. One mechanism proposed here that would accomplish this is a supra-agency regional human management decision-making center.

The New Mechanism: A Decision Center Model

To facilitate the discussion, I will speak in terms of state-level action, although the concepts advanced here could be applied at higher and lower levels of geopolitical organization.

A state law would establish the legal framework by which expenditure of public funds through human service agencies would be regulated. Among other things, this law would establish a workable coordinating mechanism for such agency services, and would vest regulating powers in an existing or new state-level department or office, or in a special commission appointed by the governor for that purpose.

The coordinating mechanism would consist of a new type of agency interposed between society on the one hand, and the more traditional agency structure on the other. It would ascertain that human management options are administered in a fashion more consistent with a cost-benefit rationale. I will, for the purposes of this paper, call this agency a human management decision center.

The coordinating mechanism would apply to all agencies funded fully or in part by the state and to all clients served by such agencies, as well as to clients served at public expense by agencies not funded by the state. In other words, generally no state funds would be expended for human management purposes not subsumed under the scope of the coordinating mechanism. It is quite conceivable that many agencies not supported by state funds, and some service systems such as the Red Feather conglomerates, may voluntarily place themselves within the coordinating mechanism.

It is obvious that in larger geopolitical systems such as states, the coordinating mechanism will have to be established in the form of a number of decision centers, perhaps with one central administration. These centers may have to be established on a regional basis, and/or on the basis of broad service areas classified essentially by human conditions such as mental retardation, mental "illness," physical and sensory disorders. While socio-historical antecedants may require such a classification at first, a preferrable system that may become more feasible in the extended future would merge the functions of "special condition" centers into primarily geographic centers dispersed so as to be conveniently accessible to the population.

The function of a decision center would be threefold:

1. It would serve as a depository and clearing house regarding service agencies and operations within its problem and/or geographic area. Agencies would apprise each other, the center, and the public of their plans and operations.

2. It would become the screening point for clients for all service agencies within its scope. In other words, clients would no longer apply to an agency for a specific service, but they would go, or be referred to, the appropriate center to state their problem.

Center personnel (to be discussed later) would conduct diagnostic and evaluative procedures, but only to the extent necessary to determine eligibilities and to provide a basis for the next, crucial step: option offering.

3. The key to the entire mechanism lies in the option offering concept. The center, having conducted its evaluation, will select from the eligible options those that are believed to have optimal cost: benefit ratios. Here it should be recalled that a decision center would have at its disposal all options offered by all the agencies within its scope; thus, the center would have more options available, and a better opportunity to optimize management, than any traditional agency functioning in the tradition way.

In most cases, it should be possible to offer clients more than one option believed to carry desirable cost:benefit ratios. Thus, a client could choose the one option most congenial to him; however, from none of the agencies within the scope of a center, or of parallel centers in a region, would the client be able to obtain options not offered to him by a center.

Once he has chosen his options, the client is referred to the agency or agencies that will implement them. By keeping an up-to-date (automated) record system, the center will avoid errors in offering options already pre-empted, or in assigning clients to agencies whose service load is full. One of the many advantages of the center system is that with crowded service loads, options that are less than optimal but immediately available can be identified and offered, at least on a short-term basis, thus saving the client agency shopping, endless waiting lists, etc. In a geopolitical area where options are few and service supply short, centers are in a much better condition to allocate services on a cost-benefit basis than on some other inefficient basis, such as one heavily influenced by mere time, as under the sequential waiting list system in which priority on the waiting list rather than priority of need determines service allocations.

The new scheme would also permit the constructive employment of a number of variations. For example, of a number of effective service options, a client would ordinarily be offered only those that are judged to have favorable cost:benefit ratios. However, the client may prefer an option which, though judged effective, had also been judged inefficient. In such a case, it may be justifiable to give the client his option if he is willing to pay its full cost (or cost differential) out of private means.

An important point in conceptualizing the new policy and mechanism is that clients would no longer be perceived as applicants for a specific service, but as individuals who state a problem. True, clients may see themselves as applicants for a specific service, but this would change as the rationale for the new scheme becomes better understood.

Specifically in human problem areas where parents are perceived, in effect, as possessing the right to "give their child away," a cost-benefit management policy with a practical implementing mechanism would be likely to open options rarely utilized today. For example, parents with a child that is severely impaired mentally would no longer be perceived as coming to a center with a specific service request such as institutionalization, although the parents may verbalize such a request. Instead, such parents would be perceived as having a problem requiring relief, and it may be found that a number of options may be equally effective, appropriate, and eventually acceptable to the family.

Even where a family situation is such that no service options are considered adequate for retaining a (problem) child in the family, such a situation need no longer be considered as implying institutionalization; it may only imply removal of the child from the home, for adoption or foster placement.[3] As the literature has amply documented, many institutionalizations are totally unjustified. A Cost-benefit scheme would prevent most such child removals; where such removal takes place, the new scheme would facilitate possibilities other than institutional placements in many instances.

The system, of course, requires that agencies relinquish certain of their traditional prerogratives, primarily those associated with intake practices. Because of the agency-centeredness and inertia of most social agencies, this must be accomplished by law, at least in regard to publicly supported operations. Such law would also transfer to the coordinating mechanism many decision-making practices now held by couts and tribunallike bodies, e.g., those bodies that currently make institutionalization decisions in many states regarding the mentally retarded or mentally "ill." However, preserving much of the current agency structure within the new system would have the advantage of making the transition from a clinical to a cost-benefit base more feasible, while preserving the strength of the clinical method in the individual encounter between professional and client after option decisions have been made.

The single regulating body for a state, mentioned earlier, would develop and periodically review guidelines which would underlie the evaluation and service option offering process of all the human management coordinating centers in a state. Such guidelines would standardize the human management process to a good degree, and remove many inequities.

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[3] A more extensive discussion of rationales for removal and institutionalization of a retarded family member is presented elsewhere (Wolfensberger, 1967).

Decision Centers and Traditional Assessment Functions

The argument may be advanced that a decision center is merely a version of the traditional multidiciplinary assessment center or clinic where the nature of a client's problems are determined ("diagnosed") and where appropriate referrals to services, mostly to be rendered by other agencies, are made. However, there are some crucial differences between the two models:

1. Decision centers, unlike traditional assessment clinics, would make binding decisions as to which agency may or may not accept a client for service at public expense. This implies a degree of administrative control not possessed by the traditional assessment services.

2. Decision centers would not necessarily engage in the extensive, even exhaustive, assessment process that has been traditional in diagnostically oriented clinics. One reason for such extensive studies has been the location of many assessment centers in universities where extensiveness of study was believed to serve in the teaching and training of professionals. A center would carry assessment only far enough to be able to reach a decision as to which service options to offer. Indeed, it is conceivable that after preliminary review, a client may be referred for a traditional and exhaustive assessment study to an agency such as a clinic, and further case processing may even be made contingent upon such a study. A critical point here is that under the new policy, the agency to which the client is referred for the traditional assessment would not make any further decisions or referrals at the end of its study, but would return its findings and suggestions to the center for evaluation and utilization.

3. Decision center staff would not be involved in any services other than evaluation and option offering. Thus, they would not have affiliation with, or responsibilities for or to, any specific service or service agency. In a sense, they would exercise a judicial-like function. In contrast, most traditional agencies not only conduct eligibility and other evaluations but also offer services themselves. By being divorced from the service process, a decision center should find it easier to maintain perspective on larger issues and to make option decisions consistent with broad social policy and on the basis of cost-benefit criteria, as most traditional agencies did not, could not, and would not do.

Decision Center Staffing

The staff of a decision center, aside from clerical and supportive personnel, would have the following characteristics:

1. If the center coordinates a specialty area (e.g., mental retardation), most staff members will have to have special experience in this area.

2. The staff will have (or, because of lack of such training at present, must acquire) skills in evolving option decisions based on cost-benefit considerations discussed above. Universities would have to introduce appropriate training in these concepts and skills into their programs.

3. So far, we are speaking of specialty skills practiced by otherwise traditional staff. However, a center, in order to mediate societal values, should aslo utilize personnel from atraditional sources and in atraditional ways. I am suggesting the inclusion of attorneys and intelligent laymen on center staffs. Indeed, I would urge the inclusion of representatives of the typical consumer of services in a particular specialty area. For example, in a mental retardation center, I would suggest the inclusion of a parent of a retarded child as a staff member.

Unusual Opportunities and Options Under the New Policy

It is possible that the new policy and mechanism proposed could facilitate certain opportunities seldom exercised at present, and that the advantages of these would be so massive as to alone justify the new scheme. The opportunities are the prospects to develop family subsidy and foster care as major options, and of basing service operations on an empirical foundation.

Family Subsidy

At present, clients with problems are often rendered services of low efficacy and/or efficiency, merely because such services may be the only ones available. Effective and efficient alternatives may be denied because they may be unorthodox or inadequately sanctioned. Family subsidy appears to be such an unorthodox and inadequately sanctioned alternative to many service options. For example, at present, a family may apply for, and be granted, institutionalization for their retarded child. The average yearly cost of exercising this option in the United States in 1966 was $2,610 (United States Department of Health, Education, and Welfare, 1967), most of it in public funds. With increasing institutional cost, and increasing life spans, it is variously estimated that an admission today may cost the public $100,000-$350,000 over the lifetime of the child. However, what the family may really have needed was temporary emotional, physical, or financial relief; and institutionalization may only have been requested, and granted, because of lack of alternative options. Adequate relief could have been obtained if the mother could have bought herself a washer, a dryer, and a dishwasher; if she could have hired a baby sitter or homemaker for a half-day a week; or if she could have gone on vacation once a year. Any of these could have been accomplished for perhaps $500 a year, i.e., a fifth of the first-year cost of institutionalization.

At present, financial family subsidies of the type just described, and outside of ordinary "welfare" channels, are virtually nonexistant. One likely reason they are nonexistant is that such schemes appear to have been ideologically unacceptable to the public. In other words, a highly cost-beneficient and quite ethical option has been unavailable because it has been inconsistent with socio-political ideology; and one probable reason why this option has been socio-politically unacceptable is lack of a clearly defined social policy resting on cost-effectiveness concepts and supported by a workable mechanism.

Foster Services

Foster care, especially of handicapped children, has been dogmatically held to be unfeasible. However, experience in California, England (see Norris in this volume), and elsewhere indicates that the dogma may have been one of the agency myths that permeate the human management field. We are now beginning to find that foster care of large numbers of handicapped children may be feasible, particularly if backed realistically by more money and fewer preconceived and stereotyped demands for love. It is indeed ironic that many children have ended up in the high-cost and low-love setting of an institution because the medium-love of relatively low-cost foster parents was judged as being insufficient by an agency.

Under the cost-benefit scheme, children appropriately (or even inappropriately) removed from their families could be fostered, and the foster program could be supported financially to the degree necessary to make this option available, effective, and yet also efficient.

An Empirical Base for Services

Another advantage of a cost-benefit policy would be that research, especially evaluative research, would by necessity become an integral part of service operations. To date, research has been considered a luxury or a nuisance rather than a necessity in human management practice. Services have rarely been built upon a research base, and they are rarely evaluated empirically. Some human management practices that have been employed for decades and that have cost hundreds of millions of dollars, and untold other resources, lack either empirical validation or comparative cost accounting, or both. Indeed, in some cases the evidence is stacked against practices which are very expensive and widely followed. It is ironic that a low-cost drug with relatively minor effects and a small market may undergo more evaluative research in a year or two than is conducted on major social action programs in a decade. Obviously, acceptance of a cost-benefit policy would call for a way of thinking consistent with the full integration of service and research, and the coordinating mechanism would make it possible to conduct research more efficiently and on a larger scale than heretofore.

The Challenge of the Unusual Opportunities and Options

I propose that the family subsidy option may constitute a cornerstone to any human management policy built on cost-benefit concepts, and that an aggressive foster program could become a major rather than minor option in mental retardation specifically. Virtually all human services need better cost-accounting and validation such as can be provided by research. Therefore, a mechanism which will make the meeting of these challenges more feasible, acceptable, and workable should be pursued with vigor, and we should be prepared to sacrifice some of our convenient traditionalisms in order to obtain such a system.

A Review Process

A cost-benefit policy is likely to result in great improvements in service continuity and efficiency. However, it does reduce client control over services, at least in localities where a range of services would be available. Thus, an error by a center in regard to problem assessment and option offering could have more deleterious consequences than it would in a system that makes "agency shopping" by a client easy. For this reason, it appears desirable to structure a review mechanism to which citizens can take recourse if they feel that a center has committed wrongs or errors in option offering.

To minimize expensive and time-consuming court involvements, a review and appeal board could be established. Possibilities are to have a single board for a state; a board for each geopolitical service area; or a board for each group of specialty (e.g., mental retardation) centers within a geopolitical service area or state. Such boards could function as advisory bodies to the state agency that regulates the center system; however, the specifics of board structure and function are less important at this point than the basic concept of a fair review process, short of (but not exclusive of) court action, available to a citizen.

Conclusion

So far, I have mentioned residential services and retardation only tangentially and as examples of broader issues. The reason for this should now be obvious: within a cost-benefit system of human services, consideration of residential service problems can only take place in the context of considering the continuum of service options; and problems related to mental retardation can only be considered in relation to other human problems generally.

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Part VIII: Overview

Chapter 17

Action Implications, U.S.A. Today

Gunnar Dybwad
Brandeis University

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ACTION IMPLICATIONS, U.S.A. TODAY[1]

The contributions to this volume have brought together the best thought available today in the realm of services in mental retardation. It is an impressive collection and one that adds substance to our hopes for a better future for the retarded. In this final chapter an attempt will be made to pull together the main trends of thought and relate them to issues which need to be faced in our country and our states, and by our Federal Government as much as by the citizenry at large.

This discussion has been structured around six broad areas of concern: philosophies and concepts; strategies of change (e.g., planning legislation, research, evaluation); human management programming; administration and financing; manpower and staffing considerations; and location and design of facilities. Obviously, there will be points which have relevance to more than one area; while there will be some cross-referencing, a point will generally be discussed in the area to which it appears to be most relevant.

Philosophies and Concepts

Without a doubt, as far as the future of residential (as well as many other) services[2] is concerned, the concept of normalization presented in Nirje's chapter has emerged as the most important one in this book. Developed in Scandinavia where it had long been reflected in the broad network of human welfare services even before the particular term was adopted, this concept is elegant in its simplicity and parsimony. It can be readily understood by everyone, and it has most far-reaching implications in practice.

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[1] The author wishes to acknowledge his great indebtedness to Wolf Wolfensberger for considerable aid in the conceptualization and formalization of the material in this chapter.

[2] There is need to clarify some terms that influence the way people think. One should think in terms of "residential services," as indicated in the title of this volume, rather than "institutions," a term which refers to congregate care practices of the past--but not of the future. "Residential services" is also more appropriate than "residential care," which implies a more narrow concept. Finally, the term "residential services" is appropriate in the plural, referring not merely to a relatively unitary concept such as embodied in the traditional institution, but to a range of diversified and specialized services as described by Tizard and Dunn.

The normalization principle draws together a number of other lines of thought on social role, role perception, deviancy, and stigma that had their origin in sociology and social psychology. It implies programming on three distinct levels.

1. On the first level, a deviant individual, in our case a mentally retarded person, should be enabled to behave in such a fashion that he will be perceived as non-deviant or at least less deviant. Nirje has outlined in considerable detail the course of action that is implied. Briefly, normalization entails helping a deviant person, within the limits of his capacities, to learn to speak, act, groom, eat, dress, etc., like typical[3] persons of his age and sex. In other words, on this level, normalization parallels many of the practices of rehabilitation.

2. On the second level, the main task is to interpret the deviant person to others in such a fashion as to minimize his differences from and maximize his similarities with them. Here communication assumes great importance. It makes a big difference whether an adult person is presented in a normal tone of voice as "Mr. John Smith," or somewhat condescendingly as "John," or, in whatever spirit, as "a mongoloid." Interpretation can, of course, also be nonverbal. A person who is housed in a tile-decked hall with a drain in the floor and an open toilet in the corner and who is seen going about in diapers or an ill-fitting hospital coverall is, of necessity, perceived as a creature which bears little relation to a human being.

We must keep in mind that interpretation of this nature has a circular effect. It affects not only outside observers but also those who work with the interpreted person. Thus, an attendant who constantly sees retardates exist in zoo-like surroundings will cast them into the animal role and will, in turn, himself assume the keeper role. Similarly, an institutional worker who sees retardates in an environment which makes no developmental demands and which emphasizes the deficiencies rather than the strengths of residents will come to believe that they are not capable of growth and learning. In turn, a mentally retarded person will tend to go along with this "nonlearning" role that is thrust upon him.

3. On the third level of programming for normalization, emphasis is on molding attitudes of the public so as to make it more accepting of deviancy in general, including deviancy in intelligence,

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[3] The term "typical" is chosen here because it refers more clearly to a statistical concept such as the median, or mode, in contradistinction to the term "normal," which evokes controversial theoretical notions regarding the nature of normality.

education, appearance, manners, dress, grooming, speech, etc. The deviancy of the retardate will be diminished to the degree that ordinary citizens gain a broader perception of normality and become accepting of a wider range of variation in the performance, appearance, and capability of fellow human beings.

Four highly interrelated concepts of residential service can be derived directly from the normalization principle. These are integration, dispersal, specialization, and continuity.

Integration

Integration refers to those measures and practices which maximize a retarded person's community participation. Obviously, there are degrees of integration. Maximal integration is achieved by the retarded person who lives in an ordinary family setting in ordinary community housing, who moves and communicates in ways typical for his age, limited though they may be, and who utilizes, in typical ways, typical community resources such as schools, churches, hospitals and clinics, bowling alleys, swimming pools, and job placements. For others, this pattern of maximal integration is not feasible; they are in need of one or more specialized services, and must be restricted in certain ways or excluded from certain commonly enjoyed activities. The important and too frequently neglected point is that one restriction, exclusion, or limitation should not automatically invoke a host of others merely because this is in keeping with the perceived pattern of mental retardation.

Individualization is an essential feature of normalization and assures social approval while granting maximum integration into those normal life patterns of which a retarded person is capable at any given time. Individualization, in turn, requires recognition of basic human and individual patterns of growth and change, of the rise and wane of needs. Hence there must be provision for periodic review to make certain that services are not only instituted but also terminated in keeping with changes in needs.

We are finding increasingly that special grouping of retardates is not always necessary in order to meet special service needs. Thus, we are gradually moving away from the traditional concept of special education via segregation, and toward a concept of special education which utilizes to the maximum possible extent regular public school and other educational services, and which provides special instruction to meet special needs with a minimum of segregation.

Dispersal

Here, one of Nirje's principles is of the utmost importance: every effort should be made not to congregate deviants in numbers larger than the surrounding community can absorb and integrate. Among other things, this principle implies that a large number of small facilities should be developed and dispersed, not only so that there are residences in the various population centers of a state but so that these residences are dispersed within these communities.

Obviously, neighborhoods will differ in regard to what they can absorb. In all likelihood, upper lower-class neighborhoods of medium density population and with a large array of resources (post office, library, churches, playgrounds, movies, stores, etc.) will be capable of absorbing mentally retarded persons at a high rate. Thinly populated upper-class suburban areas beyond easy walking distance from community resources would probably be least suited.

Dispersal is also likely to enhance rehabilitation. First, normalizing opportunities associated with dispersal are likely to increase social skills, in contrast to habilitation programs in institutions where each habilitative measure is likely to be counteracted by powerful abnormalizing and dehumanizing conditions. Second, dispersal permits placement of residences near industry and work opportunities, again in contrast to many institutions which either have more residents than surrounding business can absorb in unskilled and semiskilled jobs or are located far from employment opportunities in general.

Specialization

Dispersal is difficult, perhaps impossible, to achieve without specialization of residential functions. It is inconceivable that a small residence in a neighborhood could adequately and simultaneously serve all those functions that the traditional institution serves. In other words, a small residence could not serve both the newborn infant and the senescent, the mildly and the profoundly impaired, the well-socialized and the ill-socialized. Nor, as pointed out by Wolfensberger, Nirje, Tizard, and Dunn, is it desirable to perform omnibus functions in one residence even if one could.

Dispersal not only serves the principle of normalization but, as Dunn has so well analyzed, it also opens up new possibilies for manpower utilization and economy. Particularly in urban areas, it will be possible to draw from such a large number of retardates needing residential service that hostels with very strongly focused functions and very homogeneous resident groups can be constituted. Thus, many hostels can specialize on becoming inexpensive "sleeping homes." Others could house residents who stay only from Monday through Friday, and who return to their families on weekends. In addition, there can be hostels where resident children attend ordinary community schools during the day, or where resident adults go to regular or sheltered jobs in the daytime. But school attendance and ability to work in the community in open or sheltered employment are by no means necessary prerequisites for hostel living. As Denmark has long proven, aged and infirm adults can also profit from this normalization, provided they do not have acute medical and nursing needs. In short, a considerable portion of the institutionalized population in the United States could fit into this scheme if the necessary community services (schooling, employment, leisure-time activities, day care) were developed concomitantly.

Continuity

Continuity of personal functioning is important in achieving normalization. This requires a continuity of available services, and a continuity between those aspects of a person's life which are supported by special services and those which are not.

The concept of a continuum of available care goes back to one of the recommendations of the President's Panel on Mental Retardation, but the word "available" has been added to underline that while an inclusive array of services must be in existence, the retarded individual would not necessarily be in care on a continuous basis, and would not be moved automatically from one service to the next. There may be periods when his family or, later on, he himself can manage without aid--yet as soon as the need arises he should be able to move back into a service system that will aim at "minimizing his disability at every point in his life span" (President's Panel, 1963). Services may well be given under a variety of governmental and nongovernmental auspices--the term "system" should connote a coordinative cohesion which bridges administrative or functional fragmentation.

In regard to residential services, continuity implies an uninterrupted interplay between the family and the residential facility where the mentally retarded person is being served. Just as entrance to a residential facility should be gained easily and informally, so ongoing contacts--correspondence, telephone calls or inquiries, visits by the family and visits to the family home or relatives' homes--should be easily accommodated. A very important aspect of this continuity refers to the closest possible involvement of the appropriate family member(s) as far as crucial decisions in the service process are concerned.

Concluding Considerations

It is obvious that integration, dispersal, specialization, and continuity are inseparable. Dispersal permits the development of small living units in neighborhoods in which integration becomes possible. Continuity, especially between home and residence, further facilitates integration because it supports those ties that most citizens have to their families.

The far-reaching implications of the normalization principle--simple as it is--should now be apparent. Unfortunately, the simplicity of a term or concept is not necessarily an asset when one considers the desirability of making it the springboard for large-scale social action. There is a danger that people will brush aside a concept they consider simplistic and self-understood, without bothering to explore its concrete implications. It is therefore particularly fortunate that in 1966, David J. Vail, a well-known psychiatrist and administrator of the mental health and mental retardation facilities in the State of Minnesota, published a book entitled Dehumanization and the Institutional Career. In this brilliant work, Vail provides a detailed documentation of the many ways in which our institutions serving the mentally ill or the mentally retarded go about stripping from the residents their human dignity, their identity, their motivations, their privacy, their basic human rights. In short, not only does Vail's book provide the most cogent reason for adoption of the general concept of normalization, but item by item it would be possible to put into juxtaposition for every example of dehumanization given by Vail a corresponding situation characteristic of the process of normalization.

Several of the contributions to this volume make it very clear that the principle of normalization applies to the parents as much as to the mentally retarded himself, and indeed to the role of the family as the generally accepted social setting for interaction between parents and their children. Since Cooke's free choice principle essentially aims at assuring for parents of mentally retarded children the kind of access to a multiplicity of services which usually is (or ought to be) available to individuals in our society who are faced with a problem, it appears to have a straight logical relationship to the process of normalization. This is underlined by the fact that even though Sweden is almost wholly committed to public services, Nirje in his chapter specifically speaks of the desirability that parents have available to them choices in making decisions on behalf of their retarded child.

But what is the relationship of Wolfensberger's cost-benefit scheme to the normalization and free choice principles? At first glance one may be tempted to see a basic contradiction between free choice and the bureaucratic decision-making apparatus through which Wolfensberger's principle would have to be carried out. What needs to be emphasized is that his proposal is predicated on a human management approach, an approach which is based on human factors such as the psychological needs of the child and the parents, and the best way to meet them. To imply that his proposal would allow a bureaucratic organization to force the parent to select whatever course of action is cheapest is to pervert grossly his proposition. To the contrary, he rightly points out that in many cases today, parents are pushed or led into wrong decision-making simply because they had no access to information which would have spelled out for them the entire range of alternatives of care available to them in planning for their retarded child.

Strategies of Change

Throughout the United States, one can observe isolated examples of excellent specialized programs for the mentally retarded which have been in existence for many years, but which have not been adopted or adapted by other states or communities. A large number of professional workers, representing many disciplines, have written reports on outstanding services for the mentally retarded in other countries, and have furnished elaborate documentation through the printed word and photographs. Numerous committees and commissions in many states have reported on needs and available services for the mentally retarded, and have made sweeping recommendations for improvement. Of particular significance, of course, was the nationwide effort towards comprehensive statewide mental retardation planning which was a very important piece of the legislative program of President Kennedy enacted by Congress in 1963. Yet, with all this, progress has been slow, and has been particularly unsatisfactory in the area of residential services. Therefore, it is of great importance to search out and identify those phenomena which appear to constitute obstacles to change, and those which might facilitate it.

Obstacles to Change

The Societal Role Perception of Retardates as Deviants. The still widespread perception of the retarded person as a menace or a subhuman organism provides a particularly prominent obstacle. Fear of the mentally retarded has led community groups to protest not only the location of a workshop or a hostel for retarded young adults in a given neighborhood but even the establishment of nursery classes in public school buildings.

Usually, various role perceptions underlie use of terms and language which can be change inhibiting. A typical example is the language of the medical model so well described by Wolfensberger; this language constitutes a major obstacle to the conceptualization of a nonmedically oriented residential developmental program for those retardates whose primary needs are not in the health area.

The Momentum of the Current Service Pattern. The sheer extent, size, and monetary value, and the economic utility to certain communities, of the current physical plants, facilities, and services for the mentally retarded tend to block or delay action toward change. On the one hand, the objecting vested interests are very strong, and on the other, changes, in order to be effective, have to be of a radical, almost revoluntionary rather than evolutionary, nature.

The major professional organization in the field, the American Association on Mental Deficiency (AAMD), which could exert a powerful influence on the course of events, unfortunately has traditionally, and to a large extent to this very day, been oriented towards the conventional, institutional model. Thus, AAMD has tended towards the endorsement and strengthening of the present system rather than to a searching appraisal of the degree of its continuing usefulness and to the identification of the service areas which need restructuring. The recently introduced AAMD program for nationwide evaluation of state institutions for the mentally retarded is symptomatic of this situation. This evaluation system is oriented toward quantitative improvements in current institutional models rather than towards qualitative change through innovation. Even at that, there are no provisions for censoring or incisive reprimand for even the most undesirable, most dehumanizing practices. Indeed, the procedure of having institution superintendents evaluate each others' institutions could have resulted in little else.

Another problem develops when a state, or planning area, becomes too rigidly locked in on a long-range plan. Even when a new approach is developed, those in the system may be so involved in implementing it and in giving or developing services that there is lack of time and opportunity for thought and re-evaluation which might identify needed change. This relates to an often-observed resistance of institutions to consultations on a system level. Consultation at this systemic level can address itself to policies, basic concepts, priorities, and organization, and changes in these areas can often lead to more effective utilization of existing limited manpower, and to great improvement in services on the clinical level. Instead, less effective assistance and consultation on the clinical level alone is much more frequently sought and more readily accepted. Yet services at this level can be extremely inefficient or even futile if the basic systemic structure and process of the agency need change.

Obstacles to change are by no means to be found only in projects started long ago. Planning of recent origin can and does contain such obstacles, and the risk is particularly great when the planning includes residential facilities. For instance, Connecticut has justly received considerable accolades for pioneering a community-oriented regional system of programming for the mentally retarded. The focal point of Connecticut's regional system is the regional center. As Klaber points out in his chapter: "....in theory, a regional center could function in rented space in an office building with its director and coordinators never giving direct assistance to retarded persons." In the early stages of developing this plan, the Connecticut authorities, however, decided to structure the regional center as a building complex including a "small" residential facility accomodating up to 250 beds. The resultant problem--the tail wagging the dog--appears to bear out a theoretical formulation, developed by Sarason in this volume, which refers to situations where the overall purposes of a setting become secondary to the purposes of its component parts. Sociologists recognize a similar phenomenon in the conflict between latent and manifest (the real and the apparent) functions of organizations.

Administering a "little institution" housing 100, 150, or more individuals is a major responsibility which invariably brings with it tasks of an urgency which must take precedence over tasks related to situations where the responsibility for 24-hour care rests elsewhere, e.g., with the family. Once the regional system is thus tied to centers where administrators, planners, and staff are confronted with constant and immediate responsibility for a sizable group of handicapped residents, its potential to change and to develop other service alternatives is gravely jeopardized.

Looking at the problem of change from a broader nationwide perspective, it seems that one can characterize the present development of mental retardation services in the United States somewhat as follows: although there has been widespread advocacy for increased emphasis on nonresidential services, the need for residential services is perpetuated and reinforced by the placing of a low fiscal priority on nonresidential services and a high fiscal priority on maintenance and construction of residential facilities. This results in a shortage of nonresidential services, which, in turn, leads to an accentuation of the urgency for the creation of additional residential services which are storing up an ever larger number of individuals, since those ready to return to the community cannot be released because of the inadequacy of the supportive nonresidential services. A vicious circle, indeed.

Legalism as Change Inhibitor. A number of well-intended but rigid legalisms have interfered with change and progress. Originally designed as protective measures, they now produce an overprotection that is in striking contrast with rehabilitative needs. Typical of this are cumbersome procedures for commitment, admission, and various forms of release, and building codes such as those which make it virtually impossible to construct group homes which do not contain dehumanizing features.

Staff Concern With Job Status, Job Security, and Job Opportunities. In the past, institution attendants were generally among the lowest paid state employees, frequently had to work long hours, were excluded from civil service benefits, and lacked union organization. While pay, and in some jurisdictions hours, may still leave much to be desired, attendants are now more frequently protected by either union organization or civil service or by both. However, civil service regulations and union agreements have a tendency to become rigid and thus interfere with innovative and flexible programming.

On the professional side, a similar phenomenon can be observed. Certain medical and nursing groups have staked out jobs as their preserve and vigorously resist changes in programming that could lead to more dynamic and diversified services, since their group might then lose jobs, roles, and status of which they may now be the only holders.

Denial of Reality. The need for change can be effectively repressed by denying unpleasant realities which would underline the urgency for change. For instance, it is considered bad form for workers in the field to publicly label the gross inhumanities which are being committed upon residents of institutions. Those who expose the atrocities will find themselves much more sharply attached than those who commit them. Blatt and Kaplan's (1967) Christmas in Purgatory is one example, and another from a related field is the excellent documentary film Titticut Follies, which depicts the process of dehumanization in an institution for deviant offenders. Even Senator Robert Kennedy had to experience that the people of the State of New York had very little interest in listening to an account of the horrible conditions existing at a large state institution located within the boundaries of New York City, and they were even less inclined to do something about them. The reference in Sarason's chapter to "eyes that do not see, ears that do not hear, minds that deny the evidence before them" is very much in place here.

One paradoxical but successful maneuver has been administrative protests against invasion of the privacy of institution residents, hereby blocking exposure of institutional practices which result in routine denial of privacy, rights, and dignity of residents.

A kind of patriotism, state chauvinism, or even parochialism also plays a definitie role: the great state of . . ., proudly proclaiming its preeminence in industry, finance, culture, and education, cannot afford to let it be known that with all its riches, its glittering state office buildings, its highways and freeways, it treats in its institutions human beings, children among them, day by day in inhuman ways.

Chauvinism was even apparent in reactions to early drafts of this volume, because it has drawn heavily on contributions of foreign thinkers in the field. This offended the sensibilities of a number of people. One objection raised was that cultural differences are such that experiences and practices in foreign countries have little or no relevance to us. Such reasoning can be seen only as defensiveness.

It should be obvious to any reader that while many program specifics may be culture-bound, many other program specifics, and above all, program principles, are very generalizable and probably even universal. Thus, the normalization principle first developed in Scandinavia appears to have universal validity. Comprehensive services, under a single administrative umbrella, for clearly defined, relatively small, geopolitical units such as cities or counties, as exemplified by Copenhagen, and by Malmohus and Essex Counties, are clearly applicable to the United States, as is apparent by the Connecticut program.

Progress as an Obstacle to Change. While technical progress usually is change producing, it can sometimes serve to strengthen the status quo. An all-too-typical example here has been the routine dispensing of tranquilizers and similar drugs to large numbers of residents in institutions for the mentally retarded.[4] On the face of it, this seems preferable to the traditional method in poorly managed institutions of having large numbers of residents in handcuffs or straightjackets. However, the "modern" drug method permits human managers to take advantage of easily accessible and easily imposed external control, dispensed as needed medication, rather than to develop programs which place reliance on human interactions and which teach the residents internal controls.

Bureaucratic Subversion of Public Policy. Public policy is usually identified by programmatic statements emanating from top public officials or governmental commissions and by preamble statements of statutory enactments. A more realistic appraisal of "true" public policy can be achieved, however, through a comparative review of budget requests and legislative appropriations. Pursuit of the second approach will show that despite about ten years of constant emphasis on the development of nonresidential facilities in the community on the part of public officials, commissions, professional and civic groups, efforts to enlarge such programs are usually met with the greatest resistance, whereas hundreds of millions of dollars are made available for new construction (and inevitably increased maintenance costs) of residential facilities. Legislative discussion, if any, centers on how many institutions or how large an institution can be afforded, and hardly ever on a searching realistic exploration of alternatives to residential care. The phenomenon we observe here is known to sociologists as "system maintenance": bureaucratic structures develop a powerful drive for self-perpetuation and repulsion of outside influences which might be change producing. Expressed public policy raises the citizen's hopes, but then frustration sets in as the bureacracy substitutes emasculatory changes in place of the "true" public policy.

The fact that proper attitudes are so essential to the change process may explain why a number of small states have made great progress, while some of the worst institution conditions are found in some of our largest and richest states. In a small state, a mere handful of persons in key positions need to possess good attitudes; in a large state, a hierarchy of hundreds of individuals may stand between a new idea and its implementation.

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[4] Institutions in the United States are under a barrage from drug firms whose "detail men," aided by various enticements, push for a steady increase in the use of a large variety of drugs. The situation is such as to suggest the need for a nationwide survey of the use of drugs in institutions for the retarded, and the relationship of drug usage to the promotional practices of the drug firms.

Facilitators of Change

From the foregoing review of obstacles to change, we now proceed to define means and ways of facilitating the change process.

Change Orientation. First and foremost, it is important that those associated with institutions, no less than those associated with any organization or agency, attempt to make a conscientious and sincere commitment to the process of change. Change must not merely be allowed to happen, nor does it suffice to develop a vaguely favorable attitude toward it. What is needed is the adoption of conscious strategies of change, especially strategies that appear to be consistent with sociological knowledge and established experience.

Likert and Lippitt (1953) identified certain conditions that must exist before people are ready to utilize the methods and findings of science. One of these ingredients is problem sensitivity, i.e., there must be awareness of shortcomings and problems in prevailing practices. Another ingredient is a belief that there are better ways of doing things. These two conditions are probably complementary; if one truly wants to improve things, one should first perceive and admit the existence in one's field or agency of inadequacies, archaisms and anachronisms, lack of validity of theories and procedures, and inefficient, perhaps invalid and even harmful, practices.

Strengthening the Empirical Orientation of Services. As Wolfensberger has pointed out in his discussion of cost-benefit rationales, the introduction of a service system built on these rationales would make it necessary to consider research as an integral part of service operations. One of the many advantages of a service system incorporating cost-benefit principles is that by the very nature of cost-benefit operations, the system will be tied to research designed to evaluate the comparative validity, benefits, and costs of alternative service practices and options. Inherent in such research is quality control and the ascertainment of the degree to which day-to-day procedures of management are consistent with the stated policies of the agency.

However, large-scale operational research in institutions for the mentally retarded has been comparatively rare to date. Granted that research can not be straightjacketed in a rigid operations schedule, and that we must put a premium on the creativity of the research worker and therefore grant him sufficient freedom and independence in his pursuit, what could be more uneconomical than the hundreds and thousands of small ad hoc research studies undertaken disjointly and haphazardly in the hundred-plus institutions for the mentally retarded in the United States.

If we wish to underpin consideration of needed changes in mental retardation programming in general and in residential services specifically with solid research findings, there is first of all the need of posing the right questions to the research workers. Since studies aimed toward change must of necessity include an assessment and analysis of that which is to be changed, we are back at a point repeatedly treated in this chapter and book, namely, the reality of the present inadequacies in institutional care. To assess these fully, the research staff must be given free and unhindered access to the totality of the institutional situation without exception. Important as these research efforts are, their value will be limited by the fact that, of necessity, they must be largely retrospective. All the more it is necessary to provide generous federal financing for evaluative research to be built into new designs for human management practices and facilities.

The term "built-in research" should be applied rather literally to the construction of new facilities. Questions as to the desirable size of units, the number of people in different age groupings to be accommodated in one bedroom, the size and shape of rooms, the type of furnishings, the influence of acoustics or the type of floor covering, dining procedures, the proper arrangement for sanitary facilities, etc., will eventually be answered with greater certainty if the administrator, the architect, and the research worker, supported by the appropriate behavioral experts, will work out a scheme whereby different "settings" will be created so that these can be compared in terms of their effect on residents, staff, and cost. With availability of federal financing it should be possible to conduct collaborative and/or parallel research projects simultaneously in several states.

In sum, federal funds should be made available to test out on an experimental basis in one or two states (preferably of relatively small size) Wolfensberger's decision-center model operating under a cost-benefit rationale. The cost-benefit rationale should also be applied to an appraisal of federally supported research efforts in the field of mental retardation generally. It is always somewhat dangerous to guess in advance the result of a research assessment, but there have been some very definite indications that the millions (one could probably say scores of millions) of dollars spent in recent years on research, quasi-research,aand evaluation projects have provided us with very limited returns. Partially, these limited returns are probably a result of the cautious, conservative, and unimaginative research grant proposals which have been elicited, reviewed, and approved. The question which suggests itself is whether we would not be further ahead in practical knowledge if money had been made available from federal sources for some carefully evaluated projects of daring experimentation with innovative services.

Federal funds should be appropriated for such research, and special procedures should be instituted to elicit and review bold, imaginative, innovative, and well-designed research and evaluation proposals in the service area. One possible mechanism would be to convene one or more conferences of innovative thinkers in the field in order to discuss and define ideas and proposals. Some of these proposals could then be selected for implementation, and workers in the field could be encouraged to submit _specific_ proposals that could be reviewed competitively in regard to quality of design, cost, and likelihood of the applying investigators and agency to be able to carry out the study.

Encouragement of Healthy Controversy. Vigorous exchanges of viewpoints, and the airing of far-out concepts, new and old, appear to be an important medium of change. Thus, disagreement over practices and policies should be encouraged rather than inhibited. Such controversy should be encouraged even if it may be at times painful, unpleasant, or embarassing; the field has been much too apt to be concerned with the feelings of the administrators of institutions rather than with the feelings of the inhabitants. The American Association on Mental Deficiency in particular owes it to its professed objectives to enter actively into the many controversies which have been raised in recent years and to use the pages of its journals to reflect these issues. When institutional mismanagement, brutality, and indolence occur newspaper exposes perform an essential public service; however, of necessity they are "shot from the hip," and therefore all the more the profession should discuss in its journals the vital issues concerning practices in administration, rehabilitation, and therapy which are put into question through these "explosive" situations.

By the same token, institutions should actively seek the establishment of study and review committees, rather than having investigations and reforms thrust upon them. Such committees can be established to concern themselves both with the institution as a whole as well as with specific departments or activities, as suggested by Blatt.

Governmental Study. A mechanism of which the present book is a manifestation is government study, both on the national and the state level. Such study on a long-term basis is likely to have very salutary effects on the field. Already the federal government has made a vital contribution with its sponsorship of the President's Panel on Mental Retardation and the President's Committee on Mental Retardation, and its support of a nationwide effort for statewide comprehensive mental retardation studies. However, the very comprehensiveness of these studies on the one hand, and on the other, their coverage of only one state at a time, constituted a severe limitation. What is needed are studies jointly sponsored by the federal government and a number of states which will analyze, on a comparative basis, certain acknowledged problem areas in the field of residential services for the mentally retarded, leading to meaningful recommendations which relate to the reality encountered in the studies.

On a national level, relatively narrow but important areas within the broader scope of the subject matter might be singled out for study. For example, the President's Committee could sponsor the development of a handbook on normalization, spelling out in as much detail as possible, normalizing features of services and buildings.

Change in Governmental Granting Practices. The government can do much more than appoint study groups. It can give new directions by exercising greater discrimination in its granting practices. Federal legislation is needed which not merely encourages new service patterns but discourages continuation of the old ones. If the federal government will undertake the kinds of study suggested above, there would be increased likelihood that Congress would make it possible for government agencies to award grants more selectively. Thus, grants could be awarded to institutions that have shown evidence of their willingness to change, rather than to make awards in the hope that these will lead to change. Those states could be given priority which are actively supporting dispersal and integration of residential services, rather than states which continue to enlarge existing large institutions, or which place new residential facilities in remote locations.

Parents of Retarded Children as Change Agents. Aside from brief references in the chapters by Bank-Mikkelsen, Grunewald, and Klaber, relatively little has been said in this volume on the role and functioning of parents of retarded children in the field in general and in residential services in particular. Yet the official record will show that in Denmark, in Sweden, and also in Connecticut the associations of the parents of the mentally retarded not only played a most significant supportive role in the development of the service models described in this book but entered into the preceding conceptualization and social engineering in a very decisive way.

There are many other examples from the international scene showing parent associations as effective change agents. In the United States, the National Association for Retarded Children (NARC), with its research fund and distinguished research advisory board, contributed substantially to a change in scientists' view of this field as a legitimate and worthwhile area for scientific inquiry. From Canada, the Ontario Association for Retarded Children mobilized international interests in the special physical training needs of mentally retarded children and adolescents. In Western Australia, it was the parent associations which introduced a specialized clinic for the study of the mentally retarded in a setting since taken over by the state. In England, the National Society for the Mentally Handicapped contributed substantially to a change in service concepts for the severely retarded by the establishment of a national training center and hostel at Slough and of vacation and short-stay homes. Finally, in a symposium held in Stockholm in 1967, the International League of Societies for the Mentally Handicapped developed new formulations of the individual rights of the mentally retarded which have been recognized widely as the forerunner of a whole new conceptualization in the field of mental retardation, underpinning the broader concept of normalization.

Yet there has been and still remains in some quarters considerable uneasiness about an involvement of parents of the mentally retarded in the development and administration of services and in planning for change. Administrators are far more ready to extend to them their sympathy, guidance, and concrete assistance than to acknowledge them as active participants in the process of social programming. On occasions when representation of citizen interest on civic bodies, committees, and study commissions is involved, the opinion is likely to be voiced that representation from the parent association is not desirable, since they are too close to the problem. Yet when it comes to discussion of agricultural problems, farmers are not content with having leading citizens represent them, and physicians will not even recognize committees dealing with health matters on which they are not prominently represented. One often hears the stereotyped objection that parents and parent groups are interested only in immediate solutions and lack or are unwilling to apply long-range viewpoints. Yet the same can be said of administrators of public programs, and in recent years parent associations have repeatedly objected to the expediency of make-shift relief measures and insisted on adequately thought-out, long-range programming.[5]

Unfortunately NARC has lost much of its original forcefulness, and particularly in the area of residential care it has not been aggressive enough in informing the general public, legislative bodies, and key professional organizations of the disgraceful situations in our state institutions, involving gross violation of state law and state standards, gross lack of the most essential pieces of clothing and bedding, gross violation of residents' civil rights, and instances of cruel and inhuman punishment, unjustified use of restraints, and prolonged detention. Of all these matters no one has a more penetrating knowledge than NARC's membership, but not enough has been done to use this knowledge strategically for the ultimate benefit of the institutionalized mentally retarded children and adults, who are so desperately in need of a forceful advocate.

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[5] An example of this occurred in Illinois, where the parent association successfully objected, in spite of long waiting lists, to the construction of an additional residence building on the grounds of an already over-large institution, even though they were informed that their objection might delay availability of additional bed space.

Volunteer and Citizen Contribution. A vital factor on the American social scene is the volunteer, and in this particular context, the volunteer who as an interested citizen activist gives freely of his time to participate vigorously in organizing, guiding, and critically reviewing and appraising human welfare services in his community, his state, and his country. As an independent citizen without vested interests in the subject matter, he is often an ideal person to call to public attention disturbing developments which require change, such as the existence of dehumanizing, unworthy, or inadequate services to other human beings. To the degree that it requires controversy to accomplish this, he can and should create such controversy. To the degree that sustained publicity is required to elicit public concurrence, he is in a position to develop it. In the role of ombudsman, adopted from the Scandinavian model, he can introduce a new pattern of safeguarding the rights of the mentally retarded, of their parents, and also of those who work with the retarded. Citizen volunteers can perform an invaluable service by gaining the support of individuals or groups in the community who for various reasons are opposed to the initiation and maintenance of services and facilities on behalf of the mentally retarded. Without the help of volunteers, change may be long delayed; with their active participation, change may be considerably accelerated.

It is of vital importance that there be always consumer groups and citizen activists who retain their freedom to criticize the established agencies and policies. Thus, such consumers and activists should be careful not to be maneuvered into situations of financial or other dependency upon the agencies they should survey. However, agencies such as institutions, state departments concerned with institutions, and other service systems could increase their orientation to change by employing some intelligent, alert consumers as well as attorneys as staff members in order to actively seek out ways of safeguarding the rights and welfare of the clients, investigate complaints, and communicate with citizen and consumer groups.

If, in this fashion, citizen volunteers, consumer groups, professional organizations, and government collaborate as equal partners on the local, state, and national level, they will constitute a powerful force for change and for accomplishing a vital social task.

Needed Crash Programs. In a consideration of the entire problem of change, and of the most feasible and appropriate ways of bringing change about, there is one painful aspect that has to be faced. This is that conditions in some institutions are so bad that sudden revolutionary, rather than slow evolutionary changes are needed. When a natural disaster occurs, citizens and government will respond with a crash program. Some of our institutions are disaster areas, and require emergency measures for change.

However, mere money cannot bring about the needed changes. Among the greatest obstacles are the attitudes in the minds of those who administer institutional programs, not merely those on the institution level but also those on the state level. It may be necessary to remove from office those individuals who see retarded persons as subhuman, or as human but primarily as menaces, as diseased organisms, or as incapable of growth and adaptation. In their place, it is essential to have individuals who see the retarded as human beings, as citizens, and as developing, adaptive persons.

Here, it is worthy of note that among present program administrators, Vail's (1966) book on dehumanization and Blatt and Kaplan's (1966) pictorial demonstration of the subject have not produced much apparent effect. Can the field trust those who are so comfortable with the status quo? Can it rely on them for leadership toward the needed changes? How is one to utilize persons who do not perceive the evidence before their eyes and ears?

Needed Documentation. Early in this chapter we have discussed the sad consequences of the unwillingness to face the realities of cruel, harmful, and inhuman treatment in institutional settings. Through recent years the opposite has also been noted by competent observers in this country: an unwillingness to acknowledge the validity and indeed the existence both in our country and abroad of new and vitally different service measures and facilities, and of their success. Obviously, what is needed is careful comprehensive and convincing documentation, documentation that can not only be utilized to persuade responsible administrators, legislators, and citizens leaders, but that can also be utilized to train staff to assist in the change to new approaches, procedures, and techniques. The motion picture or video camera in the hands of a skilled and sensitive photographer who is, in turn, guided by a small team of experts can bring back results which will be well worth the expenditures, particularly as these results can not only be made available so readily on a nationwide basis to residential facilities and the responsible state departments but can also form invaluable teaching tools in various institutions of higher learning.

Human Management Programming

Human management seems to be a most appropriate vehicle to introduce the concept of normalization into the service delivery systems on behalf of the mentally retarded. In this section, an attempt will be made to reinforce points stated elsewhere in this chapter regarding the change and reorientation that must be effected in our pursuit of these new objectives.

Obviously, normalization for the mentally retarded individual can best be maintained and safeguarded if this principle is brought into play at the very beginning of his lifespan. And this, of course, implies that normalization must govern and apply equally to the parents of the mentally retarded child. A great deal has been written on what needs to be done to improve counseling and informational services to parents, particularly at the time they are informed of the fact that their child is or is suspected to be mentally retarded (for an exhaustive survey of this, see Wolfensberger, 1967; Wolfensberger & Kurtz, 1969). But very little has been done and is presently available to assist the parents in their child management, particularly in cases of severely and profoundly retarded children, who often manifest even in the very earliest developmental stages special needs, and who create special problems which are most disconcerting and puzzling to the family.

The beginnings of the process of dehumanization become quickly evident when institutional placement is recommended for a severely impaired infant who at that particular time does not offer special management problems, as is common with the child with mongolism. Not only is a low level of expectation urged upon the parent at a time when there is little clinical basis for such prediction but services are withheld or put into question which would be extended to other children as a matter of course. The key slogan, so well known to many parents, is the phrase "Why bother?" Why bother with remediation of minor physical defects, why bother with intensive health supervision, why bother with feeding problems, etc.? And all too often in the background there is the question, Why keep him alive? Usually, this is unspoken, but in 1968 a professor of theology wrote in one of America's most sober magazines: "In dealing with Down's cases, it is obvious that the end everybody wants is death," and he made quite clear that he meant death by the physician's hand, at or immediately after birth (Bard & Fletcher, 1968).

Of course, the cautious member of the medical association is not likely to make such a drastic pronouncement in a specific case, and is even less likely to act on it. Instead, he may accommodate himself with the recommendation that the child be immediately placed in an institution, often coupled with the suggestion that the mother not see the child. Official policy notwithstanding, this is still an all-too-frequent occurrence in the United States. It is not the point of this discussion to judge or belabor the difference between the physician who practices euthanasia at birth, the physician who recommends lifetime banishment to an institution, and the physician who waits for the first serious illness as the appropriate opportunity to terminate life by withholding available therapy. The emphasis here is on the broader implication of this viewpoint, which, in a less acute form, simply conveys: my practice (or our clinic) is too valuable to be concerned with "this type of case." And in the process, the parent is segregated and de-normalized along with his child.

Thus, human management service in mental retardation must be predicated on the availability to the parent of the same array of diagnostic and informational, therapeutic and supportive services that a forward-looking community must make available to all its infants and young children. The fact that the mentally retarded child may need more of these services and need them in greater intensity than the average child should not mean that parent and child are segregated into a special service from the time of the child's birth.

For the mentally retarded child, next in importance to maintenance of life is maintenance of his place within the family, even when clinical, educational, social, or rehabilitative factors may require his physical absence from the home on a short-term or a long-term basis. An important implication of this for human management is that the parent should participate to the greatest possible extent in significant decision-making in all stages of programming. And it needs to be emphasized that this should extend even to significant decisions made in and by an institution where the child may be a long-term resident.

Participation of parents in the decision-making process relative to human management services on behalf of their child should be paralleled by a continuing effort to maintain and strengthen the ties between the child and the family during periods when removal from the home is necessary. Even though it may appear trite and redundant to state once again that services away from home should, with very rare exceptions, supplement rather than supplant the role of the family, there is a real need to emphasize that the parent should have access at all times to his child, and every effort must be made (including subsidy where this is necessary) to have the child visit back in the home during periods of residential care. Frequent, sometimes prolonged, visits have proven their value in preventing undue prolongation of residential care.

At present, there is widespread belief that the current ratio of about 1.0 residential place per 1,000 persons in the population is inadequate, and the length of institutional waiting lists are frequently cited as evidence. Also, it is widely believed that the need for residential places is related to the desire of many parents to sever themselves permanently and completely from their severely and profoundly retarded children. However, there is good reason to believe that to a significant degree the present demand for placement is increased by four extraneous factors:

1. The inadequate or even misleading counseling given to parents at the time they first become aware that they have a severely handicapped child.

2. Prevailing negative community attitudes toward severe disablement.

3. The severe degree of frustration within the family engendered by a lack of community service, including appropriate medical services, which would diminish the family's burden.

4. The deplorable conditions of institutions, and especially the offensive and literally sickening state of the wards for severely disabled young children, which produce in the family on the one hand revulsion and, on the other, feelings of guilt; both reactions quite naturally contribute toward increasing separation from or abandonment of the child.

Thus, despite the overwhelming evidence that has been publicized over the past 10 or more years, it is still unfortunately necessary to emphasize that the stated need for residential services for the mentally retarded must be related to the absence of basic human management services in infancy and early childhood. While some people may feel inclined to dispute this statement, its justification is easily demonstrated by a realistic and objective yardstick: money appropriated for this purpose from local, state, or federal public funds. The facts in this regard have been stated over and over in this report: money is available to the tune of hundreds of millions of dollars for construction or renovation of institutions, but is most scarce and in many areas of the country totally nonexistent for the development of such supportive services for the family as home consultation and guidance from public health nurses, nutritionists, physical therapists, and child development workers; homemaker services, babysitters, day care or occasional night care; and short-term residential care where there is need for crisis intervention or planned relief for the family.

A plan which was recently approved in principle and supported with an appropriation by the Douglas County (Omaha, Nebraska) County Commissioners specifically proposes the establishment of a Crisis Assistance Unit (CAU), with 12 beds for short-term residential care during family crises. The CAU would also provide less than full-day residential care both for crisis and stress relief, and thus give parents the reassuring knowledge that there was a "back-stop" service to aid them as need would arise (Greater Omaha Association for Retarded Children, 1968a, 1968b).

Another innovative service worthy of experimental government support is vacation homes. Under NARC or other sponsorship, a series of camps and homes could be set up at strategic locations. These facilities would specialize on providing vacation resources. One would think that even if the full cost of such a service had to be borne by the parents, there would be enough of them to support several such facilities if they only existed or were well known. The utility and success of such vacation homes has been amply demonstrated in other countries such as England, Germany, and Scandinavia.

Tizard (1968) and Klaber in this volume have found that it is the social organization of our present residential institutions for the retarded which is the main factor responsible for the poor quality of care which many of them provide. This highlights the need to direct our attention to the extent which the traditional hierarchical staff organization at institutions for the mentally retarded has brought on a situation deleterious not only for the resident but also for the basic care staff. Adequate human management requires that priority be assigned to the upgrading of this basic staff with whom rests the greatest share of day-to-day contact with the residents. Upgrading must occur in terms of salaries, qualifications, and last but by no means least in terms of status both in relation to the rest of the staff and in relation to parents and to persons outside the immediate realm of the residential facility.

As an example of needed change, reference can be made here to the regulation, still in existence in many institutions, that the basic care staff is not to discuss the residents' functioning, that this may be done only by the physician or another designated member of the administrative staff. It is encouraging that from within the ranks of the basic care personnel has come recognition of the anomaly of their situation (Carter, 1968).

The normalization principle also provides helpful orientation as to which type of staff should render human management services in residential centers. Obviously, mentally retarded residents with acute medical and nursing problems should be cared for by a highly qualified nursing staff. Similarly, special psychiatric services must be available to children and adults with severe behavior disturbances. However, as has been brought out innumerable times in recent years, a very considerable percentage of children in these institutions do not have such problems, and therefore the obvious answer for them is to have staff acquainted with good common child care as long practiced in good children's homes. Tizard (1968) and his colleagues in England have likewise stressed a need for a child care orientation in institutions serving mentally retarded children, and have put into question the suitability of a nursing background.

Unfortunately, discussion of this very crucial subject matter in terms of planned change meets two critical obstacles. One that will be dealt with in a later section of this chapter pertains to job security and union rights. The other is a more subtle point: a hesitancy on the part of administrators to put into question a nurse's qualifications to care for children on the one hand, and, on the other hand, to face the nurses' displeasure for having questioned their suitability for the task when their devotion to sick children has been so amply demonstrated.

The point, of course, lies in the very word normalization: mentally retarded children need a normal environment and not the formal environment of nursing which has been developed in our hospitals. A good example of this formalism was encountered in the planning for a new residential facility in an eastern state. The plans centered on small units serving eight individuals with two of such self-contained units within each building. Even though these buildings were designed for an ambulatory group, the supervisory nursing staff insisted not only that in each of the self-contained units of eight there be a nursing station, but in addition that in each building there be a separate nursing office, even though in each of the units of eight there was provided a staff sitting room with adjoining toilet. The formal trappings and prerogatives of the nursing profession had to be preserved at all costs.

Normalization in human management services runs counter to an expedient employed with increasing frequency, namely, the all-purpose center designed to meet in one building-complex and often under one roof all the needs of the mentally retarded. Normalization implies the kind of separation of functions usually encountered in normal living. Children leave home to walk to school. Adults leave home to go to work. As Norris points out, this separation of function also implies that the child should not encounter the houseparent in the classroom in the role of a teacher. Implications of the principle of normalization in terms of the child's physical surroundings in residential care are discussed in a separate section devoted to architectural considerations.

Administration and Financing

Administration

"Please note that under the mental hygiene law a person defined as mentally defective is one mentally ill and since mentally ill under the Mental Hygiene Law has equal significance with the term mental disease, it follows that an institution that cares for mentally defective is an institution for mental diseases. . . ."

This quotation from an August 8, 1967, letter from the New York State Department of Social Welfare and pertaining to a private residential facility serving retarded young adults engaged in agricultural and industrial work projects illustrates a major source of the administrative problems that have been and are encountered in the development of mental retardation services. Administratively and fiscally, the mentally retarded person is claimed by the psychiatric profession as belonging in the realm of mental illness, but literature, service statistics, and psychiatric training abound with evidence that scientifically and clinically, psychiatry has been indifferent to mental retardation and largely still continues to be so.

In all the larger states of the Union one can observe a longstanding tradition that the problem of mental retardation belongs into the power structure directed by the psychiatric profession, i.e., into a department or division of mental health. As a logical consequence, the claim is made that institutions serving the mentally retarded are psychiatric institutions and must be developed under the medical model, i.e., by staffing key administrative positions on the state as well as institutional level with medical personnel and by viewing, interpreting, and structuring institutions like hospitals. Against this administrative construct stands the reality of the institution-made-to-look-like-a-hospital: the day-to-day routines encountered by the residents are not merely overwhelmingly devoid of the procedures of what the literature considers good psychiatric management, but are in many ways grossest violations of accepted psychiatric principles. Furthermore, the majority of the persons in institutions (excepting a few specialized facilities) are rarely in need of acute medical care, nor do they have acute psychiatric disturbances except for those that have resulted from the deleterious climate of the institution itself. The personnel problems which arise from this paradox of medical power structure in an essentially nonclinical setting will be reiterated in a later section on manpower. What needs to be added here is that typically the strongest force next to the superintendent is that of the business manager or steward who is geared to efficient management.

Efficient management is without doubt a useful concept but only if there is clarity as to the objective of such management. The irrationality which characterizes the management of residential facilities for the mentally retarded in this country is that it is related to the narrow mechanical objective of maintaining an institution rather than to the only tenable broad human objective, namely, the rehabilitation, education, and ameliorative treatment of the residents. The first objective considers the institution as an independent, self-fulfilling entity and is strictly internally oriented. The second objective looks upon the institution as one of many interdependent facilities and services, and judges its efficiency primarily in terms of the adequacy of residents' responses to its education, treatment, and rehabilitation programs.

While human management effectiveness is, of course, a universal consideration, it is of the most crucial significance in the field of mental retardation, where, speaking from a purely fiscal point of view, 3 or 4 years of intensive, high quality, multifaceted training and rehabilitation at $7,000 a year must be contrasted to the alternative of a routine program of institutional "care" over 25 or more years at $3,000+ a year.

Interdisciplinary Administration. Human management for the mentally retarded involves a multiplicity of disciplines (education, medicine, psychology, nursing, rehabilitation, social work, and others). Yet, true interdisciplinary collaboration is rarely encountered as a pattern of the administrative process. All the more significant is the concept of the directorate sketched by Bank-Mikkelsen in his description of the Danish mental retardation service. From the psychiatric side, Maxwell Jones (1968), the well-known British psychiatrist, recently pointed out: ". . . multiple leadership is probably the most important aspect of leadership, and it is here that there is the greatest need for change. The hierarchical structure of institutions, whether medical, industrial, or political, invest the leadership role with enormous power . . . . Multiple leadership means the distribution of authority and power to many people, and even more important to people who communicate freely in groups .... The principles of multiple or group leadership are difficult to apply to hospitals and infinitely more difficult to apply to the community".

While the principles of dispersal and specialization recommended throughout this book would lessen the problem of multidisciplinary leadership, the process of regionalization will definitely bring this problem increasingly to the forefront, because the regions will encompass a wide array of services under different professional auspices. Already we have witnessed that in spite of an initial recognition at top level of the separate needs of mental retardation and mental health (mental illness), the procedure adopted in several states has been to make the regional mental retardation director subject to the supervision and direction of the regional mental health director, even though the latter in most instances has little or no working knowledge of or interest in the field of mental retardation.

Regionalization and the Traditional Institution. A considerable problem in effecting a reorientation from the large central institutions to small, dispersed, specialized residential centers derives from the fact that the large institution exists and occupies a position of strength, while the new structures, i.e., the regional and community centers, in most cases must be newly developed and are too small and too informal to counterbalance the large institution. Eventually, of course, the network of community services will constitute a major force, but in the meantime there is danger that the reality and convenience of the existing large institution will suggest unsound modifications of the plans for regionalization, dispersal, and specialization. For instance, it may appear expedient to develop smaller community residences as "satellites" of the large institution, or, similarly, to use the accommodations of the institution as bases for the development of regional services. Obviously it will be difficult to effect the necessary changes toward regionalization and dispersal in a state where the large state institution has for many years been the focal point for services to the mentally retarded.

The absence of effective or appropriate state regulations, standards, and controls of and for state residential services for the mentally retarded has been a serious problem throughout the country. It certainly would be foolish to assume that the greater visibility of the smaller facilities recommended throughout this work and by many previous commissions and reports would obviate the need for regulatory supervision. While regionalization, dispersal, and specialization will assure greater benefits to the mentally retarded, they will create serious problems of management and coordination as compared with the large centralized institution. The mere fact that there will be a large number of residences of differing sizes serving a distinct variety of clients will make it essential to develop standards which will assure programs capable of meeting the needs of the individual residents, proper management, and the needed cooperation with governmental and voluntary agencies within the framework of the continuum of "available care." Therefore, the standards must address themselves not just to the facilities (as is now the case in many states in similar situations), but must include the program and the resident.

Notwithstanding the development of a large variety of smaller residential centers, states with large population concentrations will most likely continue to have for the foreseeable future large institution complexes. This last term is used to indicate the desirability that there be established functional units which could operate with a considerable degree of independence. However, in order to develop toward the necessary balance between the major types of services, state governments (and in terms of its granting programs, the federal government as well) should recognize and adhere to the principle that no money be appropriated for any type of residential facility without concurrent consideration of and appropriation for essential related nonresidential services in the community. Owing to the striking differences in structure, organization, function, and extent of mental retardation services and related other services in the various states, it is quite impossible to think of any set formula for the proportion of expenditures for residential to nonresidential services; however, there can be no question that this is one of the most crucial issues faced at this time.

Finances

The various proposals which have been made in this volume and before that by innumerable committees and commissions in regard to improvement of mental retardation programming suggest any number of fiscal proposals and solutions.

However, of immediate and paramount importance must be an all-out effort throughout the country to recognize the indisputable need for immediate adjustment of appropriations to make sure that in the future, institutions for the mentally retarded can buy enough clothing so that no resident needs to be naked, no child need be kept from playing out of doors for want of a pair of shoes or a sweater, no resident need freeze at night for lack of a blanket, and that essentials such as soap and toilet paper are available. Each of the examples just cited refer to actual situations in the recent past in the two richest states in this country, and in each case, the official explanation was lack of funds.

Of equal urgency and unrelated to any one specific plan or proposal is the need to raise to an acceptable minimum level the salaries of those to whom we entrust the major share of the rehabilitation, training, and care of the mentally retarded. The disgraceful conditions in our institutions for the mentally retarded, so forcefully pointed up by the President's Committee on Mental Retardation (1967), are related to the disgraceful salary level for basic care personnel. In one state, it was lower than that paid to exterminators of vermin; in another, lower than that of a disemboweler of chickens; and in a third, lower than that of an attendant of a public toilet. There is no escape from the fact that in some states the necessary appropriations to correct these inequities which are such a blot on our nation's record will constitute a definite burden on the public treasury. That is the price of decades of neglect!

In order to establish a rationale for public expenditures in the field of mental retardation, not only to the average citizen but to many public officials and legislators, our financial accounting should be linked to social accounting. The cost-benefit scheme proposed in the chapter by Wolfensberger should provide the necessary frame of references. Admittedly our tools for such social accounting of fiscal expenditures in the field of human welfare are quite inadequate as yet, but nothing else is as likely to speed improvement in many states.

New Avenues of Financing. One important feature of several of the new programs suggested by the various contributors to this volume is that they open up new avenues for the financing of services for the mentally retarded. For example, regionalization and dispersal make it possible to combine local and state funds to provide the matching money required under federal law for certain federal monies, some of which may not have been directed specifically to the mental retardation field.

In states where the county has to pay for part of the costs of care for its residents in a state institution, this money could be applied to various kinds of community services, residential as well as nonresidential, with or without state subsidy. Indeed, the shifting from residential care in a state institution to community-based care in the retarded person's own home or in a small community facility opens the way for a variety of federal financing, primarily under various provisions of social security and public assistance programs. Admittedly, there is at the moment a great deal of confusion as to which circumstances may be applied to which provisions (the quotation from the letter of the New York State Department of Social Welfare appearing elsewhere in this chapter illustrated such an instance of confusion), and, admittedly, some of the federal and state agencies involved are not very eager to extend these provisions to the mentally retarded. However, pressure from the local, state, and national associations for the mentally retarded and from interested citizen groups will, in time, enlist cooperation from state governments and local governmental units once these recognize the fiscal advantages, and this should lead to early clarification.

Desirable as it is to gain a greatly broadened financial base for mental retardation programming, it is necessary to caution against what has already happened in several states where unscrupulous administrators have exploited or misapplied provisions of new amendments to the Social Security Act. Thus, there have been moves to shift the residential burden of the state to the federal government by wholesale transfer of mentally retarded individuals into facilities inadequately regulated and unsuitable for them, since they were designed and maintained for persons with a different problem constellation. Here is a good instance where social accounting should negate the fiscal reasoning. Joseph T. Weingold (1968), executive director of the New York

State Association for Retarded Children, characterizes such a procedure aptly as "using the mentally retarded in the state school as the anvil on which to hammer medicaid funds from the federal government."

Certainly states should make every effort, and indeed have an obligation towards their citizens, to use all available funding sources in appropriate fashion, and censure is due to states negligent in that regard. But considerable significance must be attached to the phrase "in appropriate fashion," and certainly appropriateness must relate itself to the interests and welfare of the mentally retarded person and his family.

Finally, the conflict between principle and realism brought forth by the application of the principle of normalization to the area of financing must be recognized. On the one hand, it is desirable that to the maximum feasible extent payments for services for the mentally retarded come from the same source as those for corresponding services for the population at large, while on the other hand, long experience has shown that in any general non-earmarked distribution of funds the retarded are likely to be left out or at least disadvantaged. Temporary earmarking until the service is clearly integrated into the activity pattern of the agency may be one solution.

An Insurance Scheme for Residential Services. Of very considerable importance for future programming in the field of mental retardation would, of course, be Cooke's proposal outlined in an earlier chapter in this book for the extension of our social security system to cover residential and other service costs of the seriously mentally handicapped dependent of a participant in the social security system. As Miller (1968) recently stated in another context: "... the market approach has wide implications because it is supported on the basis of efficiency as well as on desirability of consumers' choice. To what extent does one try to make it possible for those individuals who are involved to make decisions which affect them?"

However, there are some problems which must be considered. First, such a measure might make it too easy to use residential rather than non-residential services, and would thus contribute further towards the unsound imbalance between the two. Second, parents might place their children into residences hundreds of miles away or out of state, even though equally adequate local residences may be available. This would mean that public funds were used to support probably unsuitable and even harmful practices. Third, unless such systems were subordinated to very strict control on either the state or the local level, planning of services would become virtually impossible. The need of and/or for various types of services might become so unpredictable that no economical or longrange plan could be maintained, and nursing home entrepreneurs might choose to locate their services in haphazard or inappropriate patterns. Finally, such entrepreneurs might have very little incentive for habilitation programs or the utilization of sheltered work settings. Indeed, the scheme might actually inhibit the development of habilitational programming in residential settings, since habilitation would be likely to threaten the entrepreneur's livelihood.

In any case, Cooke has injected new and challenging thoughts into the problem of service delivery in the field of mental retardation. His proposal undoubtedly should be given extensive further study before it is implemented, and such study should encompass a controlled research demonstration in one or a few states, provided that rigid safeguards can be furnished in the form of administration and regulation.

One of the inscrutable incongruences in the provision of care at public expense, not just in the field of mental retardation but in many other fields as well, is that while funds for expensive residential care are readily available, it is most difficult and in some circumstances indeed quite impossible to get public funding when opportune circumstances make it possible to provide for the same individual not only equal but superior care in a private home on a boarding or foster care basis. As Wolfensberger said: "It is indeed ironic that many children have ended up in the high-cost and low-love setting of an institution because the medium love of relatively low cost foster parents was judged as being insufficient by an agency."

A somewhat similar situation exists in regard to adoption of mentally retarded children. Admittedly this is not an easy task, and the utmost care must be exercised to protect both the interests of the retarded child as well as those of prospective adoptive parents. Still, there are people who are able, willing, and indeed desirous to undertake the task of raising a handicapped child, and with the real and expected expansion of supportive services in the community the feasibility of such an undertaking has been very considerably increased. Yet, institutions still admit many infants with mongolism for long-term (and all too often life-time) care involving an expenditure conservatively estimated at something like $100,000 to $150,000. A mere fraction of this cost, such as $30,000, would support a small adoption service staffed by two senior social workers and a secretary for 1 year. If this staff would be able to find in a year's time just one adoptive home for a child otherwise placed in the institution, the total investment in the agency would already have been justified. Therefore, it is highly desirable that states, perhaps with some federal assistance, initiate more aggressive action in this area.

Where Does the Money Come From, and Where Does It Go? Lack of money has been a major stumbling block in the past, but equally serious has been poor utilization of funds that have been available. Indeed, there is no question that the all-too-ready availability of hundreds of millions of dollars for construction purposes without preventive and follow-up services in the community has been most detrimental, as has been premature allocation of money for large-scale programming, construction, etc., when appropriation of a much smaller sum for well-controlled and evaluated community services would have been far more desirable.

As touched upon by Wolfensberger, there exists an "American illusion" that money is the answer to most problems. In other words, if one spends enough money on a defined problem, it will eventually be conquered. This illusion is sadly evident in the attitudes of many defenders of our institutional system. In essence, they cannot conceive of an alternative concept or model--be it residential or even nonresidential. Thus, we hear calls for more institutions, as well as more money for existing institutions, and unfortunately many states are taking this route, often without clear priorities assigned to different categories and alternatives of service.

In early 1967, we were spending at a rate of $600 million a year for about 200,000 institution residents. However, merely to maintain the standards and rate of current institution services will require a rapid rise in institutional costs. By 1975, we could be spending $2 billion a year on our institutions, and they could still be most inadequate. That this is a strong possibility is underlined by the fact that some public institutions with the highest per diem expenditures in this country are grossly dehumanizing.

The point is that money alone is not the answer, not to the problem of institutions or to many other problems. What is ultimately more important than money is philosophies, ideologies, and concepts, and a system of priorities based on these.

Manpower and Staffing Considerations

Several sections of this chapter have referred to personnel problems in the development of an adequate service system for the mentally retarded, and in particular have emphasized the effects to be expected from programs oriented toward specialization and dispersal of residential services. The following observations and propositions will highlight additional aspects of the manpower situation.

While state government invariably has set unreasonably high standards for the construction of residences, it has shown the greatest resistance toward making adequate allowance for even minimal standards when it comes to the staffing of these residences.

Throughout this book, references have been made to administrative arrangements and conditions, now prevailing in institutions, which create very unfavorable working conditions. It should be reiterated in this context that particularly in residential settings, careful thought needs to be given to the dignity and comfort of care personnel as well as residents.

Application of the principle of normalization to the personnel field requires that personnel on any level, working with the mentally retarded, should meet at least the same personal and technical standards as equivalent workers in other settings dealing with nondeviant groups.

Training and Recruitment

The relative newness of mental retardation as a field of professional study and the unusually rapid development of new knowledge and approaches in the field make it imperative that residential and other service agencies place strong emphasis on the development of their professional staff. Means would include adequate and accessible professional libraries; regularly scheduled staff development seminars which include persons from related disciplines, services, and agencies; and attendance at state, regional, and national professional meetings. Necessary arrangements must be made with civil service or other relevant authorities for a period of induction training of professional personnel lacking prior training and experience in the field of mental retardation.

By means of incentive grants, universities should be encouraged to develop training programs for leadership at the predoctoral level, e.g., a 2-year master's degree in retardation administration and program development. Graduates of such programs should be able to step into a wide range of leadership positions, including state planning, program administration, workshop direction, executive positions in the parent movement, etc.

To attact young people to mental retardation careers early in their academic-professional development, the SWEAT program should be strengthened and expanded.[6] However, SWEAT awards should be made very discriminatively and only to those agencies which are ready to invest a high degree of interest and guidance in the students.

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[6] See Kugel's introductory chapter for an explanation of SWEAT.

A promising innovation aimed at development of intermediate level personnel has been initiated in several states through collaboration between state agencies and junior colleges in training persons in retardation. Encouragement of such programs through financial participation of state and federal government appears desirable.

Service systems should make major efforts to utilize part-time workers, especially those who have some skill and experience in retardation but who cannot or will not work full time. This is increasingly being done in the fields of education and nursing. Administrative flexibility in scheduling would enable more housewives and students to work in the field, and would be likely to attract more students to retardation-related careers. Part-time work should be particularly easy to arrange in special-purpose hostels where residents are out working or studying during the day, so that peak coverage is required for weekends and for relatively short periods in the mornings and evenings. Finally, some hostels could permit part-time working students to live in, offering them free room and board in return for some work, and again attracting them to eventual careers in the field. The establishment of small, specialized, and dispersed hostels makes such practices much more feasible than in the past.

To help meet the need for attendants, houseparents, and houseparent assistants, states as well as governmental units below the state level should establish long-term training programs for adolescents who do not have an interest in academic careers. Properly oriented, such programs could provide a human service challenge to many young people groping for a meaningful career commitment. Some such training programs might be developed in cooperation with the public schools along the lines of the work-study models that have seen such great growth in recent years. This would permit youngsters to enroll as early as age 16. If it is advisable that the first few programs of this nature be federally supported, this might be achieved with modifications in existing manpower-oriented legislation.

Unionization as a Factor in Residential Services

Increased unionization of care worker personnel in residential facilities appears inevitable. Every effort must be made to assure the employees and their spokesman, the union, a dynamic and constructive share in long-range and day-to-day programming. At the present, unions are too often maneuvered into a posture of opposition, and then insist on rigid adherence to seniority and similar rights in ways which are detrimental to program objectives. Obviously, imagination and skillful interaction between management and union is needed to present to the union desirable alternatives to such practices. In most states, this must be done in collaboration with civil service or personnel boards, which, on their own part, need to show greater flexibility in making appropriate allowances for special needs in a residential care setting without sacrificing the essential elements of employee protection.

By the same token the promotion of care personnel in situations where union practices are no obstacle need to be examined. Promotion to middle-grade supervisory positions in many institutions is frequently not based on understanding of program objectives, skill in day-to-day work with residents, or favorable response to inservice training, but rather often results from favoritism, political influence within the institutional power-structure, or from just having put in years of service. This has brought about all too often situations where "old line" middle-grade supervisory staff stand in the way of effective program change and can neutralize the dynamic orientation and inservice training programs for new staff even if directed by carefully selected training officers.

Manpower Consequences of the Medical Model

One additional major problem in the present manpower situation in residential services arises from the pursuit of the medical model. This creates manpower problems on two accounts. First, the medical model is an illusion in the sense that most institutions have neither the resources nor the clientele for implementing a high-quality and appropriate medical hospital model. In consequence, good physicians in general avoid an institutional career, leaving the field to poorly trained or poorly adjusted colleagues and to foreign-trained physicians whose backgrounds are serious handicaps in this situation. But equally serious is a second problem. The essence of a traditional medical model is the position of preeminence reserved to the physician and through him to the nursing hierarchy. Under the best of circumstances this greatly complicates the work by competent members of other professions such as, for example, psychologists, but when the physician "in charge" is patently lacking in competence in his own field, let alone in related areas, then the institution encounters great difficulty in recruiting and keeping good nonmedical professional staff. The specialization of residences proposed by Tizard and Dunn, and discussed elsewhere in this chapter, should overcome this problem in that a service continuum would contain medically oriented and directed residences for those retarded whose major need is hospitaltype care, as well as residences for other retardates built on educational, rehabilitational, correctional, and other models directed by the appropriate disciplines.

Location and Design of Facilities

At the time of this writing, blueprints for the construction of residential facilities for the mentally retarded involving the expenditure of several hundred million dollars are on the drawing boards of state agencies throughout the nation. Most of these facilities are designed for the longevity usually expected from public buildings. That is to say, most of these buildings are expected to serve mentally retarded individuals considerably beyond the year 2000. It is all the more disconcerting that in many cases the design of these buildings reflects and incorporates concepts long considered outdated. It is hard to think of any other area of governmental activity where so many millions of dollars are expended in perpetuation of practices which have long been condemned as unsuitable and damaging in the professional literature, in the reports of governmental commissions and departments, and by concerned citizen groups.

Wolfensberger's chapter on the origin and nature of our institutional models has provided us with a careful documentation of a historical development which has led to this sorry state of affairs. To find the answers as to the reasons for its continuance despite all the protestations of recent years, one would have to look to the social scientist and his helpful interpretation of the nature of bureacratic processes and of system maintenance. The question as to how to bring about change has been dealt with in a preceding section of this chapter; in this section, the emphasis will be on what needs to be changed in regard to certain aspects of the location and design of residential facilities.

Human Management Versus System Management

To put it briefly, the traditional and unfortunately still prevailing method of designing and constructing residential facilities for the mentally retarded was predicated on and guided by system management. The new program to which this book is dedicated is based on human management. The traditional institution reflected a mass approach; the residential center of the future must be based on the needs of individual human beings.

The thought behind the traditional design was the need to create accommodations for diagnostic categories in quantity; in the new residences, services will begin with a human being, and rather than to create an environment to accommodate and maintain the level of functioning of his "category," we will need to provide an environment allowing for and indeed stimulating growth and development. Knowledge how such growth and change takes place thus becomes the key point of departure not only for the architectural design of rooms, buildings, and complexes of buildings but also for the crucial matter of site location and the perennial problem of the size of a facility. Once the architect has accepted the overriding principle of normalization and the associated concepts of integration, dispersal, specialization, and continuity as they relate to a residential human management service, he will have a tangible frame of reference within which he can design and properly locate living space that will enhance rather than hinder growth and change on the part of mentally retarded individuals (Dybwad, 1968).

Site Selection

Much has been written in criticism of the location of institutions for the mentally retarded. What needs to be kept in mind is that these selections were preordained to failure because of the way the task was defined: to find a very large tract of land on which to place a large institution (usually with the thought of further expansion) at a reasonable land cost. Frequently, this prescription led to the acquisition of land nobody else wanted, thus affording the real estate speculator with political connections a handsome profit, or a town badly in need of a supporting "industry" would find it a good investment to provide such land free of charge. As far as the residents were concerned, they appeared only as a quantity, as a figure of 1,000, 1,500, or 2,500; there was no thought, indeed there was no possibility of thinking of them as individuals belonging to a family, or any thought of that family's geographic relationship to the institution harboring their son or daughter.

Normalization impinges on site selection in several significant ways reflecting the concepts of integration, and also of specialization and dispersal. Integration implies maintaining and indeed developing not just the sense of belonging but the closest possible physical proximity between the mentally retarded and the family. This implies visits from the family to the center, and visits of the mentally retarded individual to his home. But there is another dimension to integration; the principle of normalization not only refers to the life the mentally retarded leads in the institution and his contacts with the family but also bears upon his contacts with society, usually in the context of a community. This implies that the residential center not only should be within reasonable distance of the home of the mentally retarded but should have a definite ongoing relationship with the community, a relationship that has meaning not just to the center as a social institution, not just to a staff, but also to the residents themselves.

The concept of dispersal adds to the process of site selection another dimension in the literal sense of this term. It seeks to limit the center to a sensible size in terms of human interaction, interaction of the resident with his fellow resident, interaction of the resident with the staff, interaction of the director of the center with both the staff and the resident, and finally also interaction of the center as a whole with the surrounding community. From the factors here enumerated, it will be obvious that there can be no set figure indicative of satisfactory dispersal. Much will depend on the kind of resident the center is serving, and much will depend on the interactional capacity of the surrounding community.

The concept of specialization also will play a role in site selection, at least in regard to certain facilities, for instance, centers serving individuals with acute medical and health problems call for location in desirable proximity to a medical center; a center serving children of school age should be so located that the children have an opportunity to attend special classes in a public school; a behavior-shaping oriented center should be near a college, a university, or a similar source of psychological manpower.

Some Principles for Building Design

The traditional mental retardation institution was and to a considerable extent still is being built in a fashion that might be characterized as "from the outside in," determined by such factors as the size and shape of the land available, the number of people to be accommodated in the most economical size of buildings, and the most efficient distribution of buildings on the available land, taking into consideration length of steam tunnels, required electric cables, factors pertaining to food preparation and distribution, etc. After due consideration of all these factors, plans are designed for the most economical use of the building, and eventually one arrives at the space allocated to individuals and groups. And although the prescribed minimum square or cubic footage has been provided, the result (as has been amply described in this volume) is inadequate.

If we are to move to an architectural application of human management principles, then, of course, it will become necessary to reverse the process, and to plan the building "from the inside out" (Dybwad, 1967). First consideration will be given to the space that is to be set aside as the personal territory of the resident: his bed; his bedside table; the place for his clothes and other belongings; room for the table, and for a chair if he is to have one in his room; and, of course, determination of whether he is to share his room with others. From this most personal territory, consideration would then move to the living space he would share in common with others, such as space for leisure, dining, hobbies, sanitary facilities, cloak rooms, and storage space, keeping in mind the total group that is to live in this unit, whether six, eight, or ten, but hopefully not more. Having thus outlined the resident's intimate personal sphere as well as his immediate group sphere, the next determination would be, with due consideration of such factors as age, degree of handicap, etc., whether, in what fashion, and with how many other units this first unit may be joined.

The next consideration would then be how this larger constellation will be related to the surrounding community. There is no need to go into architectural details here.

Group Homes in the Community

A very important part in the residential human management service will be played by small group residences in the community such as hostels for young men and women in vocational training, in sheltered workshops, or in open employment; group homes for children who cannot live at home but for whom foster home placement is not, or at least not yet, indicated; aged retarded men and women who are not in need of a nursing home; and a variety of temporary or transitional group homes. Some local authorities in some countries, particularly in New Zealand and Australia, have rushed into construction of hostels and other group homes with rather disappointing results; in order to make construction "worthwhile," the homes were usually built for too large a number of residents, and the design carried all the earmarks of institutional construction. Furthermore, in order to obtain land, the location was often disadvantageous, but once the land was secured, there was the temptation to erect other structures on it, and thus the workshop was just a stone's throw from the group home which adjoined the day care center.

Experience has shown that it is far more preferable to rent, lease, or buy existing residential structures which can be adapted to group home living, and Sweden has successfully pioneered in demonstrating the feasibility of using one or two apartments in an apartment house as a hosteltype group residence for mentally retarded adults.

The Old Institution: Renovate or Discard?

One of the many obstacles to the development of dispersed, specialized residential services has been the existence of the large traditional multipurpose institutions. A common argument is that these institutions cannot be "abandoned," and that in our efforts to improve the services to the retarded in the community by means of either residential or nonresidential services we cannot neglect the welfare of those retardates already in our institutions. Consistent with this are those who advocate massive financial investment in the existing institutions in order to bring the physical facilities and programs to what are considered acceptable standards.

Examination of some hard facts, however, reveals rather unequivocally that such a course of action is at best ill advised, and at worst unfeasible, and a poor service to the residents now housed in such institutions.

1. The majority of residents in our present institutions are housed in buildings which would fail to meet architectural-engineering standards. In a number of states, extensive architectural-engineer-surveys have shown that renovation of most of the older and sometimes even newer buildings costs as much or more than expenses involved in building, or utilizing existing buildings, in the community. In estimating the cost per place in these existing institutions, one must also take into consideration the costs involved in renovating supportive buildings such as kitchens, schools, activity buildings and areas, auditoriums, chapels, bowling alleys, swimming pools, and, above all, the fact that any adequate renovation will decrease the capacity of the traditional institutional building on the average by 50 percent. When the total cost of such architectural rehabilitation is averaged out, it may come to as much as $11,000 per residential place.

The remarkable point here is that after expenditures of such magnitude, one would still end up with vast and essentially segregated facilities, located in areas where today one would not place residential facilities in the first place if one applied modern concepts such as normalization.

2. It is furthermore of interest to examine the cost factors in the operation of the traditional-omnibus versus modern-specialized residences. A number of considerations are pertinent here.

The more residents a building is designed to accommodate, the stricter become the building codes that must be observed. While small residences can be built at relatively modest costs, the cost per place increases drastically when buildings are designed to house more than approximately 8-20 residents. Furthermore, buildings erected at high initial cost are much more durable and therefore impose limits upon the exercise of options as time goes by. Some buildings with relatively short-life expectancy can conceivably be abandoned after approximately 20 years so as to enable the service system to engage in continuous planning, to incorporate new concepts and ideas into buildings, and to permit flexible relocation of services. Larger and therefore more durable buildings, on the other hand, may have to be utilized for several generations. Here, we have much to learn from Scandinavia, where residential facilities are increasingly designed and constructed along lines of ordinary community housing, which has, of course, a relatively limited life expectancy.

Application of the normalization principle will guide the architect in the design of rooms and buildings which will be as close to normal living situations as is possible. Keeping in mind the principle of growth and change, he will design rooms and houses with a maximum of flexibility so that furnishings may be added as the resident learns to cope with them, large bedrooms subdivided into smaller rooms, and confining spaces opened up to provide freedom of movement. While in the earlier stages each unit should be completely self-contained and separate from other units (if located in the same building they could be arranged as separate apartments), at a later date the flexibility of design might be utilized to create certain common social rooms to be used by two or more groups together while still providing separate living space in each of the basic units for those not ready to join the larger social grouping.

Some Special Problems

A large-scale application of the normalization principle and the associated concept of dispersal would bring over the next 10 to 20 years a steadily growing number of mentally retarded persons into our cities and suburbs as residents of various group residences. That mentally retarded individuals can live in small group residences in our cities and suburbs has been well demonstrated by now as far as the social aspects of this arrangement are concerned. Together with similar developments in the area of other handicaps, this will constitute a real challenge to urban planning and should, on the federal level, gain the sympathetic attention of the United States Department of Housing and Urban Development. At the present time, the multiplicity of zoning ordinances discriminate in one way or the other against handicapped citizens. Some of them are so biased in favor of property owners and against considerations of public interest that legislative relief seems to be called for.

Another series of obstacles in the development of better residential services for the mentally retarded is created through local and state building codes, the national safety code, and a long list of local, state, and federal regulations.

The United States Advisory Committee on Intergovernmental Relations had the following to say in a 1966 publication entitled Building Codes: A Program for Intergovernmental Reform: "Obsolete code requirements, unnecessary diversity of such requirements among local jurisdictions, and inadequate administration and enforcement, taken together tend to place unjustified burdens on the technology and economics of buildings. Too many building codes contain unnecessarily high standards, prevent the use of economical methods and materials in building, and include provisions extraneous to the basic purposes and objectives of building controls." Most architects who have been involved in the design and construction of facilities for the mentally retarded would feel that this is a very mild statement indeed compared with the unreasonable and often irrational obstacles that they are encountering when trying to use informal and less expensive construction, particularly in buildings housing totally ambulant, generally able-bodied, mentally retarded children or adults.

The origin of much of this difficulty is quite clear: once again it was the medical model and its application to residential facilities for the mentally retarded that established in the eyes of all the code authorities seemingly once and for all the mentally retarded as a sick and helpless person requiring the stifling protection of the most stringent code provisions.

This is a matter of extreme urgency and truly a nationwide problem. Not only are construction costs for mental retardation residential services unnecessarily increased, often by vast amounts, because of code requirements; beyond doubt more serious is the fact that many of these code requirements geared to the needs of hospital construction give the resulting buildings some distinct dehumanizing features.

There is no attempt here to play down the necessity for uniform building codes strictly enforced. What must be put into question are building code provisions which make rigid judgments about people or groups of people which are clearly unwarranted and prejudicial. What is to be put into question are building codes which are "rigged" to favor certain industries or certain construction methods and make practically impossible or in any case uneconomical the introduction of modern, equally appropriate materials and methods which are both cheaper and more serviceable. Nor is there any attempt here to denigrate the importance of fire protection. Anyone who has worked in a responsible position in the field of the aging or in children's institutions or around hospitals appreciates the importance of good regulatory fire protection and careful fire inspections. Not infrequently it is the fire marshal who by insistence on the definitive closing of buildings long condemned as fire traps will make decisions faint-hearted administrators lack the courage to make. The objections raised here pertain to rigid classificatory judgments written into the fire codes which, in their large-scale application, are discriminatory against certain individuals or groups of individuals and deprive them without cause of basic personal rights, such as the right to live in normal rather than dehumanized surroundings.

While the subject has been introduced previously, it is dealt with here in such length because it has been largely ignored by professional and citizen groups alike, mostly because of its complicated technical aspects. This is an unfortunate misunderstanding because the question is not what kind of walls built from what kind of materials will give what length of fire protection; the question is whether young adults who leave their group residence to travel by public transportation to an all-day workshop, or a group of adult males in an institution who leave their building every morning to be used throughout the day by the state as cheap labor (driving vehicles, operating machinery, working in storehouses), can be considered by any rhyme or reason as requiring the same kind of fire protection in their living quarters as that prescribed for buildings which house 80 or more semiambulant, sickly, physically incapacitated, severely retarded young children.

Harking back to material presented earlier in this chapter, it is of course necessary to point out in fairness that the housing and fire code officials have merely reacted to traditional popular notions about the mentally retarded, and have been influenced by the picture of dehumanization they witnessed in public institutions. The need for change is obvious, and the burden rests on those working in the field of mental retardation to present well-founded and well-documented information which can be used to bring about a more rational approach to this whole matter.

Obviously research and carefully controlled experimentation is called for to convey a new and more adequate picture of the range of functioning levels and performance potentials of retardates, and to demonstrate the appropriateness of various types of construction in terms of such information. Considering that in the judgment of the President's Committee on Mental Retardation and of state commissions throughout the country, a vast number of outdated and long-condemned institutional buildings across the country must be demolished and replaced within the next 10 years, and sooner rather than later, with totally different types of buildings; and considering further that the greatly accelerated pace in accumulation of new knowledge and skills puts into serious question the past practice of erecting institutions to last for generations, one aspect needs particular attention. This is the possibility of introducing prefabrication methods when it comes to the construction of smaller and more informal residence buildings. Denmark, France, Czechoslovakia, and the U.S.S.R. are far ahead of our country in the use of prefabrication, and the Danish Mental Retardation Service in particular has successfully employed it to meet certain new and large-scale demands. A most important factor is that prefabricated methods will greatly speed construction, and no one could doubt that speed is of the essence in replacing our disgraceful human storage houses with new facilities that will permit humane management to become a reality.

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Biographical Notes
on the Monograph Authors

GUNNAR DYBWAD was born in 1909 and received his doctor of law degree from the University of Halle, Germany. He graduated from the New York School of Social Work in 1939. From 1934 to 1951, he served in various capacities in the fields of correction, delinquency, and child welfare in the states of Indiana, New Jersey, New York, and Michigan. From 1951 to 1957, he was executive director of the Child Study Association of America, and from 1957 to 1963, executive director of the National Association for Retarded Children. After 3 years as director of the mental retardation project of the International Union for Child Welfare in Geneva, Switzerland, he became professor of human development at the Florence Heller Graudate School for Advanced Studies in Social Welfare at Brandeis University, Waltham, Massachusetts. He consults widely on services and program development throughout the nation as well as the world.

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LLOYD DUNN was born in 1917 in the Province of Saskatchewan, Canada. He attended the University of Saskatchewan and later received his doctorate from the University of Illinois. From 1953 to 1963, he was chairman of the Department of Special Education at George Peabody College for Teachers. From 1963 to 1968, he has been director of Peabody's Institute on Mental Retardation and Intellectual Development. Dr. Dunn has contributed to many areas of special education, particularly to the training of professional manpower in the field and to the development of materials and techniques to assess and improve language development in children. Dr. Dunn has been president of the Council for Exceptional Children, a member of the President's Panel on Mental Retardation, and editor of the CEC Research Monograph Series. Currently, he is on a 2-year sabbatical leave from Peabody College.

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NIELS ERK BANK-MIKKELSEN was born in Denmark in 1919. He received a law degree at the University of Copenhagen in 1944. During 1944 and 1945, he worked in the resistance movement. He entered the Danish Ministry of Social Affairs in 1946, and the Danish Service for the Mentally Retarded in 1950, becoming its director in 1959. Under his directorship, the Service has experienced a sixfold growth. Mr. Bank-Mikkelsen has lectured and consulted extensively around the world, and in 1968 received the Kennedy Foundation award in recognition of his program development work.

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BURTON BLATT was born in 1927. He studied at New York University, the Teachers College at Columbia University, and at Pennsylvania State University, where he received his doctorate in special education. During World War II, he served with the United States Navy in the Phillipine Islands. He has taught special classes for the mentally retarded in New York, and held a teaching position at Southern Connecticut State College from 1956 to 1961. Since 1961 he has been a professor in the special education department at Boston University and the department chairman. He is also professor of psychiatry (education) at the Boston University Medical School. In 1967, he became Assistant Commissioner for Mental Retardation in the Department of Mental Health of the state of Massachusetts. Dr. Blatt has published numerous articles and books on a wide range of subjects.

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ROBERT E. COOKE was born in Attleboro, Massachusetts, in 1920. He obtained his B.S. degree from the Sheffield Scientific School in 1941, and his M.D. degree from Yale University in 1944. Before and after service in the United States Army he took a number of years of advanced training at Yale, and was a member of the Yale faculty from 1950 to 1956. In 1956, he was appointed Professor of Pediatrics and Pediatrician-in-Chief at the Johns Hopkins Medical Institutions. Dr. Cooke served on the President's Panel on Mental Retardation in 1961-1962, and is currently a member of the President's Committee on Mental Retardation and chairs its subcommittee on research and advancement. In 1968, he received the Joseph P. Kennedy International Award for Leadership in the field of mental retardation.

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DAVID NORRIS was born in Northern India of Irish parents in 1928. He was educated in England, where he first studied for the Church and afterwards took training as a teacher for the mentally handicapped. He has taught both the regular grades as well as classes for retarded children, and has been headmaster of a residential school for the retarded. He has also held the positions of superintendent of a comprehensive training center for the mentally handicapped and organizer of schools for the Fountain Hospital for the retarded in London. Until 1968, Mr. Norris was County Organizer of Training Centers for the Mentally Handicapped in the County of Essex. He is currently senior lecturer at the Bournemouth College of Technology, and a member of the advisory panel of the (British) National Society for Mentally Handicapped Children. Mr. Norris has published a survey of retarded children in hospitals and day schools, and studies on laughing and crying behavior in retarded children, on the effects of various teaching techniques with young retardates, and on language development in retardates. He has also written a series of books for severely retarded pupils and has recently completed a teaching film on play and development in young retarded children.

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M. MICHAEL KLABER was born in 1930. He obtained his B.S., M.A., and Ph.D. degrees from Columbia University and is a diplomate in clinical psychology. He has worked in a research position at the New York State Psychiatric Institute, as supervisor of Clinical Training at Mansfield State Training School, and as director of Psychological Services at the Connecticut Seaside Regional Center. Currently, he is director of the Mental Retardation Project and associate professor at the University of Hartford. Dr. Klaber's interests focus upon rehabilitation of handicapped individuals, on social system change, and on the utilization of psychological skills in the service of the community at large.

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ROBERT B. KUGEL was born in Chicago in 1923. He received his B.A. and M.D. degrees from the University of Michigan and took advanced training at the University of Michigan Hospital and at the Yale University Child Study Center. After spending 2 years in England as a member of the United States Air Force, he directed the Division of Child Health of the Baltimore City Health Department and, later, the Child Development Clinic at the University of Iowa Hospital. In 1965, he became director of the Child Health and Development Center at Brown University. Presently, he is director of the Growth and Development Institute and chairman of the Department of Pediatrics at the University of Nebraska Medical Center in Omaha, Nebraska. Dr. Kugel is a member of the President's Committee on Mental Retardation, chairman of its subcommittee on the state of the nation, and vicepresident for the Medicine Section of the American Association on Mental Deficiency.

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SEYMOUR B. SARASON was born in 1919. He obtained his A.B. degree from Rutgers University and his M.A. and Ph.D. degrees from Clark. After being chief psychologist at Southbury Training School in Connecticut, he became associated with Yale University in 1945, where he is currently professor and director of the Psycho-Educational

Clinic, which, in part, is concerned with research on new types of facilities for the mentally retarded. Dr. Sarason has held a large number of special assignments in the field of mental retardation, and is author of one of the basic texts in the field. Among his special interests are the utilization of manpower in human service areas, and the structure of agencies in these areas.

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BENGT NIRJE was born in 1924. He received his undergraduate training at the University of Uppsala and the University of Stockholm, obtaining a B.A. in comparative literature. From 1952 to 1954, he did graduate work at Yale University on a Smith-Mundt Bill Scholarship and at the Sorbonne in Paris. From 1956 to 1958, he worked as a welfare officer on the Hungarian refugee problem, first for the Swedish Red Cross in Austria and later for the United Nations. In 1958-59, he was in charge of the organization of the Folke Bernadotte drive for cerebral palsy. Since 1961, he has been secretary general (executive director) of the Swedish Parents' Association for Mentally Retarded Children. In this capacity, he functions as an "ombudsman."

Mr. Nirje is well known in the United States from his visits to mental retardation agencies and his addresses to parent and professional groups. He also has hosted many Americans who have visited mental retardation facilities in Sweden.

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EARL C. BUTTERFIELD was born in 1935. He attended Lewis and Clark College and Vanderbilt University and received his Ph.D. in psychology from George Peabody College for Teachers in 1963. He has held a staff psychologist position at Southbury Training School in Connecticut, and was first a research psychologist and then a research associate at Yale University from 1963 to 1967. Currently, he is an associate professor of pediatrics at the University of Kansas Medical Center and research associate of the Kansas Bureau of Child Research in Kansas City. He has published widely on the effects of institutionalization on the behavior of retarded persons, and on the characteristics, selection, and training of institution personnel.

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JACK TIZARD was born in 1919 in New Zealand, where he went to school and took his university training. Since 1945, he has lived in Great Britain. After lecturing in educational psychology for a year at St. Andrews University in Scotland, he joined the scientific staff of the Medical Research Council, working on problems of mental subnormality in the Social Psychiatry Research Unit located at the University of London Institute of Psychiatry at the Maudsley Hospital. He became professor of child development at the University of London Institute of Education in 1964. Dr. Tizard has written widely on service patterns in the area of adult training and employment, and children's residential facilities. In 1968, he received a Kennedy Foundation award for his scientific contributions to the study of mental retardation.

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KARL R. GRUNEWALD was born in 1921. He received his M.D. degree at the University of Lund, Sweden, in 1948, and in postgraduate studies he specialized in child psychiatry and pediatrics. In 1950, he participated in the Swedish Red Cross Mission to Korea, and from 1956 to 1960, he was head of the Department for Child Psychiatry at Kristianstad Hospital. Since 1961, he has been head of the Division for Care of the Mentally Retarded of the Swedish National Board of Health and Welfare. He is a member of the World Health Organization Advisory Panel on Mental Retardation.

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WOLF WOLFENSBERGER was born in Germany in 1934. He received his B.A. degree at Siena College in Memphis, Tennessee, his M.A. degree from St. Louis University, and his Ph.D. degree in psychology from George Peabody College for Teachers in 1962. In 1956-57, he served a traineeship in clinical psychology at Norfolk (Nebraska) State Hospital, and in 1962-63, he was a postdoctoral research fellow in training at the Maudsley Hospital in London. From 1960 to 1962, he served as director of Human Development at Greene Valley Hospital and School in Tennessee. In 1963-64, he was Director of Research at Plymouth State Home and Training School in Michigan. Since 1964 he has been at the Nebraska Psychiatric Institute of the University of Nebraska Medical Center, Omaha, Nebraska, where he is an associate professor and a full-time researcher in mental retardation.

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